Residential Care Staff’s Experiences of Supporting Adults with a Learning Disability Who Are Impacted by Trauma

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Abstract

Background: People with a learning disability are disproportionately affected by trauma. Despite this, there is a relative paucity of research focused on how they can be best supported.

Aim: The aim of the present research was to explore how care/support workers in residential care settings respond to and support people with a learning disability who are impacted by trauma.

Method: 12 residential care/support workers recruited through purposive sampling participated in semi-structured interviews about their experiences of supporting adults with a learning disability who were impacted by trauma.

Results: Using Reflexive Thematic Analysis, five themes and nine subthemes were generated. The five themes were: *Grappling with the meaning of trauma; Negotiating relationships as a means to helping; The emotional weight of the work; Space to think is essential* and *Navigating a dysfunctional and harmful system.*

Conclusion: Care/support workers play a vital role in supporting people with a learning disability who are impacted by trauma. A number of recommendations can be made based on the findings of this research in order to improve care for people with a learning disability who are impacted by trauma within residential services, as well as support for staff working in them.

Contents

Chapter One: Introduction

Chapter Summary

This chapter provides an introduction and sets the context for the present study. First, the overall aims of the thesis and how these will be addressed are set out. Key definitions, including learning disability and trauma, are then outlined and the issues around these explored. The history of treatment of people designated as having a learning disability, and the development of learning disability services within the UK are also discussed, along with relevant theoretical insights into the impact of trauma on people with a learning disability. This chapter also contains a systematic literature review which leads into the aim of the present study.

Aims of present thesis

This thesis is focused on understanding the experiences of residential care/support workers in supporting adults with a learning disability who are impacted by trauma. Firstly, in order to understand how health and social care services can respond effectively to people with a learning disability who are impacted by trauma, Thomas and Harden’s (2008) Thematic Synthesis is employed to conduct a systematic literature review answering this question. As detailed below, this systematic review identified several gaps in the literature where understanding of how people with a learning disability who are impacted by trauma can be best supported could be furthered. This forms the rationale for the present empirical study, which aims to answer the question of how residential care/support workers respond to and support people with a learning disability who are impacted by trauma, or who have disclosed or been identified as having had difficult life events, through the use of qualitative methods.

Learning disability

In UK policy (Department of Health, 2001), a learning disability is defined as a “significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood”. These three criteria have also been endorsed in the British Psychological Society (BPS) Division of Clinical Psychology’s (DCP) guidelines for the assessment and diagnosis of learning disability (DCP, 2015) and correspond to the criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) and International Classification of Diseases (ICD-11; World Health Organisation, 2022), under the diagnostic label of ‘intellectual disability’ and ‘disorders of intellectual development’ respectively. The diagnosis is further broken down into levels of mild, moderate, severe and profound impairment in the DSM-5 and ICD-11, with the BPS guidelines alternatively referring to two rather than four levels of impairment – significant and severe (DCP, 2015).

In the diagnosis of learning disability, ‘intelligence’ is typically operationalised with an Intelligence Quotient (IQ) score, which is garnered from assessment with cognitive batteries such as the Wechsler Intelligence Scale for Children (WISC-V; Wechsler, 2014) or the Wechsler Adult Intelligence Scale (WAIS-IV; Wechsler, 2010). An IQ of below 70 (two standard deviations below the mean) is considered to represent the level of ‘impaired intelligence’ that can be categorised as a learning disability.

Conclusions as to whether a person’s social or adaptive functioning can be considered impaired may be similarly assessed using measures such as the Adaptive Behaviour Assessment System (ABAS-3; 2015). BPS guidelines stipulate that diagnosis of learning disability should be based on clinical judgement rather than solely on whether scores on assessments meet the stated thresholds (DCP, 2015), which are essentially arbitrary (Webb and Whitaker, 2012).

Indeed, to some degree it can be considered that deciding whether someone has a learning disability or not is an arbitrary endeavour, and learning disability diagnoses are socially constructed and dependent on the demands of society at the time. For instance, Goodey (2011) comments that many years ago when the majority of the population were illiterate, this would not have carried the same connotations about intelligence as it might today. That is not to say that the needs of people designated as having a learning disability are not real. It may therefore be necessary to:

> strike a balance between, on the one hand, thinking of bodies’ abilities and limitations as given by nature and/or accident, as immutable and uncontrollable, and on the other hand, thinking of them as so constructed by society and culture as to be controllable by human thought, will and action (Wendell, 1996 p.45).

Whatever one’s standpoint on the nature of learning disability, the implications of disability as a diagnosis and label are multifaceted. On the one hand, it can open access to much needed services, but labelling people in this way can expose people to stigmatisation (Green et al., 2005).

The impact of stigma is considered by Sinason (1992) in her discussion of the terminology used over time to refer to people with a learning disability. Sinason

(1992, p.34) writes that “no human group has been forced to change its name so frequently” and describes how over time, new terms are created to avoid the stigma attached to the old, which in turn become imbued with pejorative connotations. Sinason (1992) lists a number of terms used to denote a perceived deficit in intelligence, dating back to the 13th century, although their precise meanings may have differed. Indeed,

> we have no way of knowing for certain if someone called a ‘fool’ in the sixteenth century would, if transported through time, be called a ‘simple’ in the eighteenth century, an ‘imbecile’ in the 1890s, or ‘moderately or mildly retarded’ in the 1960s; nor do we know if someone called an ‘idiot’ in 1760 would still be one in 1860, or ‘severely retarded’ in 1960 (McDonagh, 2008, p. 6).

Unwin (2022), whose son Joey has a learning disability, similarly questions the idea that these historical terms can be said to represent the same thing, while concluding

> that it was self-evident that people like Joey have always existed, however little that existence was recognised, acknowledged or named… It struck me again and again that if we forget that people with learning disabilities are (or were) real individuals, we fall into the ultimate category error, of denying them their inalienable humanity—and losing ours in the process (Unwin, 2022, p. 151).

Presently, the two most frequently used terms are learning disability and intellectual disability. As aforementioned, the diagnostic manuals the DSM-5 (American Psychiatric Association, 2013) and ICD-11 (World Health Organisation, 2022) refer to intellectual disability, and this term is more frequently used in academic literature while health and social care services in the UK generally use the term learning disability (Cluley, 2018). It has been suggested that services should adopt the term intellectual disability to bring terminology in line with the diagnostic manuals and academic literature, as well as other countries such as the USA (Schalock et al., 2007) and Ireland (McConkey et al., 2019) where the term intellectual disability is more frequently used. However, in research on the understanding and opinion of the term intellectual disability, health and social care and education professionals, and family carers of people with learning disability felt the term was ambiguous and unhelpful (Cluley, 2018). Notably absent from Cluley's (2018) research was the opinions of people who were given the diagnosis themselves. Some self-advocates prefer to describe themselves as having 'learning difficulties' (Goodey, 2016) although this may create confusion as this term is more commonly used in the UK to describe specific learning difficulties such as dyslexia. In this thesis the term learning disability will be used, as the majority of services in the UK use this term. It is important to state that no matter the term used, it represents a diverse group of people with different needs, abilities and preferences (Cluley et al., 2020).

History of learning disability and learning disability services in the UK

It has been difficult to draw conclusions about the lives of people with a learning disability in the past due to the issues around language detailed above. Additionally, and reflecting the marginalisation of people with a learning disability in society, there may have been a view that recording such people's existence was not of interest (Digby and Wright, 1997). In the UK, the earliest reference to judgments around mental capacity appear in 13th century legal documents pertaining to issues of inheritance (Turner, 2018). Learning disability 'services' did not exist until centuries later however and it seems until the industrial revolution in the mid-18th to early-19th century most people with a learning disability lived with their families in local communities (Jarrett, 2020). While some charitable asylums existed at this point, housing a few thousand people described as ‘idiots’, the earliest form of mass institutional ‘care’ was in workhouses (Wright, 2000). From the 1840s onwards, a mass asylum building programme began, coined ‘the great incarceration’ by Jarrett (2020). This was accelerated by the 1886 Idiots Act, which allowed local authorities to build asylums specifically for ‘idiots’, who were differentiated from ‘lunatics’ on the grounds that they were born ‘feeble-minded’. The incarceration and segregation of people who would today be understood as having a learning disability was further increased with the advent of the eugenic movements, which demanded that those deemed to have ‘mental deficiency’ be controlled and prevented from having children (including through forced sterilisation), lest the future of the human race be under threat (Richardson, 2005).

Upon its founding in 1948, asylums were taken over by the NHS and renamed as ‘sub-normality hospitals’. Concerns about the lack of legal protection for those resident in these hospitals was raised in the 1951 pamphlet ’50,000 outside the law’ published by the National Campaign for Civil Liberties (NCCL), which outlined how many people were detained in these hospitals for years without end in poor conditions (NCCL, 1951). The NCCL rejected eugenicist ideas and called for greater provision of community care. Despite this, by 1969, only 43 of the 227 local authorities in England and Wales had residential care provision for people with a learning disability and institutional populations had continued to grow (Alaszewski, 1988). It was around this time that the abuse and poor conditions at Ely and Fairleigh hospitals were exposed (Stainton, 2022), leading to the 1971 White Paper ‘Better Services for the Mentally Handicapped’ (Department of Health and Social Services, 1971), which outlined a plan for deinstitutionalisation. Progress was slow, with large scale closures not occurring until 1986 (Stainton, 2022). Between the 1971 White Paper and its successor ‘Valuing People’ (Department of Health, 2001), numbers of people with a learning disability in hospitals dropped from 58,850 to just short of 10,000 in England and Wales. There have been further pushes to reduce this number throughout the 21st century under the agenda of Transforming Care (Department of Health and Social Care, 2022), which was developed after further exposures of abuse at Winterbourne View and Whorlton Hall hospitals, in 2011 and 2019 respectively (Willis, 2020). Nevertheless, as of May 2024, 2025 people with a learning disability or autism are in hospital, with 53% of those having been in hospital for over 2 years (NHS Digital, 2024).

As hospital beds have been decommissioned, residential care provision for people with a learning disability has been expanded. Residential care services are staffed by care/support workers who provide 24-hour support. Services are typically small, providing an average of 5-6 residents with accommodation and personal care (Mansell et al., 2006). In 1971, there were approximately 4,900 places in residential care homes, rising to 53,400 places in 2000 across England and Wales (Department of Health, 2001). More recently, in 2017-2018, 26,570 adults with a learning disability were recorded as living in residential care homes and a further 29,975 in supported living accommodations in England (Public Health England, 2020). The most recent data available for Wales puts the numbers in residential care and supported living services at 1413 and 2491 people respectively (Hatton, 2017). It is unclear whether the latter figures encompass some of the same services counted as residential care in the Department of Health (2001) statistics, which make no mention of supported living services. Supported living services differ from residential care in that accommodation and support are managed by different providers, and so care may be provided on a drop-in basis. Proponents of supported living services propose that this allows for more flexible support that maximises people's independence (Kinsella, 1993). However, some supported living services in the UK do have 24-hour staff presence, meaning the distinction between residential care and supported living is often blurred (Mansell & Beadle-Brown, 2010). Despite the increase in residential provision for people with a learning disability, there are still shortages of placements, particularly for people whose needs are deemed to be more complex, leading to people being accommodated out of area far from their families (Perry et al., 2013).

Unfortunately, many of the issues associated with long-stay hospitals have not been resolved simply by replacing them with community services. People who were moved from long-stay hospitals into the community sometimes found themselves in settings that were different, but with care that was no less inadequate (Johnson & Traustadóttir, 2005). Describing the process of deinstitutionalisation in the US, Trent (1994) concluded that "both institutions and communities can be inhumane and exploitative; each mirrors the world around us", pointing to the marginalisation of people with a learning disability in society (Trent, 1994, p.277). Standards of care in residential and supported living services remain variable (Bigby & Beadle-Brown, 2018; Hutchinson & Kroese, 2016) and indeed, there is evidence from analysis of safeguarding referrals that suggests that adults with a learning disability living in such services may be more likely to be abused than those living with their families (Beadle-Brown et al., 2010). Poor training, lack of supervision, high staff turnover and staff shortages have been cited as contributing to poor and abusive care in such settings (Collins & Murphy, 2022). The risks associated with congregate living have also been highlighted by the increased mortality rates from COVID-19 amongst people with a learning disability living in residential care services, who by nature of living with multiple people dependent on multiple staff were less able to shield themselves from the virus (Trip et al., 2022).

The context of austerity in the UK since the 2008 financial crash has been cited as driving increasingly poor standards of care and working conditions within social care services (Baines & Cunningham, 2015). The issues resulting from long-term under-investment in services have been exacerbated by the pandemic, with providers of social care services reporting increasing difficulties in recruiting and retaining staff (Care Quality Commission, 2022) and many local authorities struggling to maintain the delivery of social care services due to budget deficits (The King’s Fund, 2024). As well as impacting on the quality of care delivered, these issues are likely to affect the wellbeing of staff in what was already acknowledged to be a stressful and demanding job (Ryan et al., 2021), with Nuttall et al. (2022) finding that the pandemic increased stress for care/support workers in learning disability services. Pay and conditions for care/support workers are often poor, with 43% of social care staff in England earning below the real living wage (Irvine et al., 2024). Additionally, social care staff are disproportionately likely to be from marginalised backgrounds (Dowling, 2021; The King’s Fund, 2024).

People with a learning disability and trauma

The term ‘trauma’ originates from a Greek word meaning a ‘wound’ or ‘hurt’ and has over time become used to refer to psychological as well as physical injury (Thompson & Walsh, 2010). While no single definition has been agreed upon, one commonly used definition is that produced by the Substance Abuse and Mental Health Services Administration (SAMHSA). SAMHSA defines trauma as

> an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being" (Huang et al., 2014, p.7).

As detailed in the above section on the history and contemporary state of learning disability services in the UK, trauma is unfortunately of great relevance to the lives of many people with a learning disability. As well as experiencing abuse in health and social care services, people with a learning disability may be subject to violence, abuse and neglect in their communities, educational establishments and family homes (Wiseman & Watson, 2022).

The SAMHSA definition does not specify particular events that can be considered trauma, rather focusing on the individual's subjective experience and impact of the event (Huang et al., 2014). Other definitions focus more on specific events, for instance the DSM-5 cites exposure to "death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence" as a precursor for traumatic stress (American Psychiatric Association, 2013, p.271). It is difficult to assess the precise prevalence of such traumatic events amongst people with a learning disability. Abuse is under-reported and under-recognised in society as a whole (Zinzow et al., 2021), and may be even more so for people with a learning disability (Willott et al., 2020). For instance, in a recent meta-synthesis, McGilloway et al. (2020) identified factors such as difficulties communicating and being understood; a lack of knowledge about sex and consent; and presumption of unreliable testimony as barriers for people with a learning disability in reporting sexual assault. If abuse is perpetrated by those upon which people with a learning disability depend on for care and protection, it may be particularly difficult for abuse to be identified (Sin et al., 2009). Additionally, there is evidence to suggest that abuse perpetrated by other people with a learning disability may not be recorded as such by care staff (Joyce, 2003); rather, it is conceptualised as ‘challenging behaviour’, a term frequently used in learning disability services to describe behaviour with potentially adverse outcomes, including interpersonal violence (McKenzie et al., 1999). Furthermore, there are challenges in establishing the prevalence of potentially traumatic events experienced by people with a learning disability as whether events are conceptualised as abuse depends on the social and legal context (Bouffard & Goodson, 2017), and some studies may not delineate learning disability from other types of disability.

Nevertheless, what evidence we do have for the prevalence of various potentially traumatic events suggests that people with a learning disability are disproportionately affected. Two meta-analyses examined research published between 1990 and 2010 into the prevalence of violence perpetrated against children (Jones et al., 2012) and adults (Hughes et al., 2012) with disabilities, including learning disability. Both found that people with a learning disability were at increased risk of experiencing violence compared to the general population, and Jones et al. (2012) noted that children with a learning disability may be at higher risk than children with other disabilities. These results must be interpreted with some caution however as both studies noted high heterogeneity in the prevalence estimates between different studies included the meta-analyses. This may have been partially attributable to some of the issues in measurement described above. Similar issues were detailed in a further meta-analysis by Tomsa et al. (2021), examining the prevalence of sexual violence against adults with a learning disability. Tomsa et al. (2021) estimated that 32.9% of adults with a learning disability are subject to sexual violence in adulthood, with men and those living in institutions being more at risk.

There is debate as to whether more narrow or broad definitions of trauma are more useful. Some argue that conceptualising trauma as a result of specific prescribed events neglects those whose experiences fall outside its boundaries but nonetheless experience distress (Tutté, 2004). Others argue that a ‘conceptual bracket creep’ towards more expansive definitions of trauma has led to its meaning being diluted by organising everyday stressors with life changing events, thus diverting attention from those most in need (McNally, 2009). Other definitions of trauma include that of Terr (1991), who introduced the differentiation of Type 1 vs Type 2 trauma based on whether the traumatic events occur singularly or as part of a series of events, with Type 1 trauma referring to sudden and unexpected events experienced as isolated incidents, such as road traffic accidents, rapes or terrorist attacks, and Type 2 trauma referring to repeated or ongoing traumatic events. Similarly, trauma is sometimes differentiated as being ‘simple’ or ‘complex’ on the basis of being related to a single, isolated event vs repeated events that are difficult to escape from (Herman, 1992). According to these definitions, being repeatedly subject to abuse whilst living in an institution would constitute Type 2 or complex trauma.

Other definitions divide trauma into Big-T and small-t traumas, with Big-T trauma being that akin to that in the APA definition, and small-t trauma referring to events that are not life threatening but nonetheless cause distress, such as parental separation or bullying (McCullough, 2002). This is also of relevance as bullying and harassment appear to be near ubiquitous experiences for people with a learning disability in both childhood and adulthood, and this is often targeted on account of their disability (Wiseman & Watson, 2022). People with a learning disability may be subject to ‘mate crime’, where somebody uses the guise of friendship in order to exploit or abuse them (Andrew Landman, 2014) In one study which surveyed people with a learning disability about experiences of victimisation, 48% of those surveyed said the perpetrator had been someone who they had considered a friend (Richardson et al., 2016). Such treatment can be seen in a wider context of marginalisation of people with a learning disability in society (Hall, 2014). As well as making maltreatment more possible, the consequences of this marginalisation means people with a learning disability are afforded less resources to cope with any adversity they may face. Many people with a learning disability are socially isolated and may have little control over whether relationships they have are continued, for instance when they involve paid staff or other users of services (Harrison et al., 2021). When people with a learning disability are bereaved, the loss they experience is often compounded by losing contact with multiple other people if the person who died was the one who kept them in touch. They may also face losing their home, and losing someone who knew them and their needs well, if the person who died was a caregiver (Blackman, 2003).

A related concept to trauma, and one that has been the focus of much research, is that of Adverse Childhood Experiences (ACEs) (Felitti et al., 1998). The literature on ACEs is focused on the prevalence and impact of 10 experiences that are considered to have a harmful effect on wellbeing when experienced in childhood – physical abuse; emotional abuse; sexual abuse; physical neglect; emotional neglect; exposure to domestic violence; parental substance abuse; parental mental illness; parental incarceration, or parental absence or loss (Oral et al., 2016). In a UK context, Emerson and Brigham (2015) found that children with developmental delay are more likely to experience such events than typically developing children. The original ACEs study found that exposure to a higher number of ACEs was associated with higher incidence of physical and mental health and substance use problems (Felitti et al., 1998), results that have since been replicated – see Hughes et al. (2017) for systematic review. The ACEs literature demonstrates that the impact of trauma goes beyond that outlined in the diagnostic criteria of either Post Traumatic Stress Disorder (PTSD) or Complex Post Traumatic Stress Disorder (CPTSD) (Bonanno & Mancini, 2012; Ford, 2015).

There is a smaller body of research concerned specifically with how people with a learning disability are impacted by trauma and ACEs. This has been the subject of a recent scoping review by McNally et al. (2021), who examined what is known from the existing literature about the experience of psychological trauma for people with a learning disability. The majority of the studies cited by McNally et al. (2021) focused on the relationship between exposure to traumatic life events and symptoms associated with PTSD. For instance, Catani and Sossalla (2015) found that abuse in childhood predicted PTSD symptomology in adults with a learning disability. They also found that those who had been abused in childhood reported higher numbers of traumatic experiences in adulthood. There is less research focused on the impact of exposure to repeated traumatic experiences in people with a learning disability, although there is no reason to believe that it would not have the same cumulative negative impact as in the general population. One study by Scotti et al. (2012) identified a positive correlation between the number of potentially traumatic events experienced and level of behaviour problems (including aggression and self-injury) in people with a learning disability. Scotti et al. (2012) also reported that 79% of people included in their study had experienced at least one potentially traumatic event, with the mean number of events experienced being 2.8, again highlighting the magnitude of the issue of trauma for people with a learning disability. Other studies cited by McNally et al. (2021) link exposure to traumatic life events to other mental health diagnoses such as psychosis and personality disorder (Clark et al., 2016) and depression and obsessive-compulsive disorder (Stavrakaki & Antochi, 2004). The presence of mental health difficulties may act as a mediator between exposure to traumatic events and aggressive or otherwise considered to be challenging behaviour (Clark et al., 2016; Rittmannsberger et al. 2020). Additionally, Santoro et al. (2018) found that childhood adversity was associated with more physical health problems in adulthood.

A separate review conducted by Smit et al. (2019) aimed to examine the literature on the clinical characteristics associated with sexual abuse in people with a learning disability. They found that as in the general population, sexual abuse was associated with a number of negative psychological and behavioural responses and concluded that difficulties with conduct, self-injury, inappropriate sexualised talk and poor feelings of personal safety may be particularly common amongst people with a learning disability who have been subject to sexual abuse. Other studies noted that the impact of trauma may be more frequently expressed through behaviour changes in people with a learning disability, particularly those with diagnosed with more a severe learning disability (Kildahl et al., 2020b). It may be that “that which cannot be spoken will be acted out” (Beail, 2021, p.15). Alternatively, it may be that increased behavioural disturbance is reported as being particularly prevalent because it is more observable to staff than internal experiences such as flashbacks, which some people with a learning disability may have difficulty communicating to others. Additionally, the dominance of behaviourist interventions such as Positive Behaviour Support (PBS) in learning disability services in the UK may lead to staff privileging this aspect of their clients' experience, something that has been subject to recent critique by Clegg and Landsdall-Welfare (2023). Clegg and Landsdall-Welfare (2023) argue that the targets of behaviourist interventions (such as aggression and self-injury) emerge from and are expressions of strong emotions, which are often rooted in past experiences. Therefore, interventions that acknowledge this are more likely to be impactful than a purely behaviourist approach that is focused on adjusting proximal antecedents and consequences. Clegg and Landsdall-Welfare (2023) draw on psychoanalytic and attachment theories to support their argument; these understandings will be given further consideration below.

Increasing concern about the frequency and impact of adverse life experiences has led to the advent of Trauma Informed Care (TIC) and Trauma Informed Approaches (TIAs) in service development. TIAs go beyond the provision of interventions that specifically target the impact of trauma, such as Eye Movement Desensitisation and Reprocessing (EMDR) or Trauma-Focused Cognitive Behavioural Therapy (TF-CBT), both of which appear to have some benefits for people with a learning disability, although further high-quality research is needed (Byrne, 2022). Rather, TIAs are designed to be embedded at a systems level to ensure services are set up to recognise and appropriately respond to the impact of trauma (Sweeney et al., 2016). TIAs also prioritise avoiding re-traumatisation through practices such as seclusion and restraint that may feel like repetitions of earlier abuse and add to the distress people experience (Sweeney et al., 2018). Other principles of TIAs include a prioritisation of safe, trusting and collaborative relationships; empowerment and choice over care provided and an awareness of cultural, historical and gendered aspects of trauma experiences (Huang et al., 2014).

The implementation of TIC is mentioned in the NHS long-term plan as a priority for mainstream mental health services, but does not feature in the section relating to the needs of people with a learning disability (NHS Confederation, 2019), perhaps suggesting that trauma is still not sufficiently on the agenda in learning disability services (Morris, 2021). There have however been some efforts to develop TIAs in learning disability services (Goad, 2022; Keesler, 2014a). The Learning Disability Professional Senate (2019) has outlined some ‘top tips’ for delivering TIAs, focused on developing awareness of the impact of trauma on people with a learning disability; provision of support and training to enable staff to work with effectively with those impacted by trauma; valuing and prioritisation of relationships between staff and people with a learning disability and readily available specialist support. Similar recommendations were made by McNally et al. (2023) who worked with service providers and people with a learning disability to develop a model of TIC for residential services. Other developments have included integrating TIC principles into a PBS framework (Harding, 2021), and Rye et al.’s (2021) trauma-informed approach to caring for people with a personality disorder and intellectual disability (CaPDID).

A central tenet of TIC is consideration of the impact of working with people with a trauma history on staff, who may themselves become traumatised through exposure to accounts of traumatic experiences and trauma-related distress (Schulman & Menschner, 2018). Amongst direct care staff in learning disability services in the USA, there has been found to be a positive correlation between the number of traumatic events experienced by service users and levels of secondary traumatic stress in staff (Boamah & Barbee, 2022), with 12.4% of staff meeting the threshold for PTSD based on this. Further factors that may influence the development of secondary traumatic stress in learning disability care staff are a lack of support within the role, exposure to ‘challenging behaviour’ and personal histories of trauma (Boamah et al., 2023). There is also evidence from the USA that care staff in learning disability services may have had a higher than average number of ACEs (Keesler, 2018). Although not specific to learning disability services, the notion that health and social care staff may be at risk of becoming traumatised in their line of work has been increasingly recognised within the UK, with the establishment of staff mental health and wellbeing hubs during the pandemic (NHS England, 2024). Some of these services have now been decommissioned as central funding has been withdrawn, a decision which has attracted criticism from some professional bodies (BPS, 2023).

Theories pertaining to the impact of trauma on people with a learning disability

Psychoanalytic theories

Psychoanalytic theories are those derived from the work of Freud and his successors. Freud was initially concerned with ‘hysteria’ - somatic symptoms for which no physical cause can be identified. Freud observed that experiences of abuse were common amongst patients suffering from hysteria and became one of the first to write about the impact of psychological trauma, concluding that “the psychical trauma —or more precisely the memory of the trauma—acts like a foreign body which long after its entry must continue to be regarded as an agent that is still at work” (Breuer & Freud, 1893 p.6). Freud believed that if people could express what had happened in their lives then they would gain relief from the associated symptoms.

Although Freud later shied away from highlighting the impact of abuse in his work (Herman, 1992), and appeared to hold a conviction that psychoanalytic therapy was only suitable for those who were relatively intellectually able (Freud, 1904), over the years a number of clinicians have used his ideas with people with a learning disability (for a history, see O'Driscoll, 2009). For instance, Sinason (1992) took Freud's ideas about defences to explain how people with a learning disability can develop a 'secondary handicap' in response to trauma, in which attempts to avoid painful feelings exaggerate the impact of the existing disability. Sinason (1992) considered that the learning disability itself can be a source of trauma, as the notion that one is different from others can evoke powerful feelings of fear, anger and shame. This can be related to the idea that there is a 'societal death wish' against people with a learning disability (Blackman, 2003). For instance, the proliferation of practices such as amniocentesis may reflect a societal belief that it would be better if people with a learning disability were not born at all, and many people with a learning disability and their families will be all too aware of this (Marks, 1999). Marks (1999) considers this societal death wish may reflect a process of splitting and projection - in our individualistic and achievement focused society, imperfection and dependency are seen as unacceptable. These aspects of ourselves are therefore kept out of conscious awareness and instead located in those who can be constituted as 'other', thus perpetuating the marginalisation and ill-treatment of people with a learning disability.

Other relevant psychoanalytic concepts include transference and countertransference. Transference refers to the unconscious transferring of experience and feelings from one interpersonal situation to another, while countertransference describes the feelings that are evoked in the person onto whom an experience has been transferred (Jones, 2004). Although transference and countertransference processes can be present in any relationship, these concepts are most often applied in the context of a therapeutic or caring relationship. Where trauma is involved, the process of transference and countertransference can be an intensely emotive one, with dynamics that are replicative of the trauma potentially being recreated (Ralph, 2001). For staff this might feel hard to bear, leading to a defensive emotional suppression (Storey et al., 2012). From a psychoanalytic perspective it is vitally important to speak about transference and countertransference and bring them to conscious awareness, in order to avoid unintentional harm occurring as consequence of these processes. This is at the centre of the previously mentioned CaPDID approach (Rye et al., 2021), which focuses on encouraging staff to reflect on the feelings evoked by their work with traumatised people with a learning disability.

Attachment theory

Attachment theory was developed by Bowlby (1969). Drawing on insights from ethology and evolutionary theory, Bowlby proposed that people have an innate drive to seek proximity to others, terming this the attachment behavioural system. For infants who are unable to physically defend themselves from threats, eliciting care and protection from others (for instance by crying) is vital for survival. Bowlby proposed that our early experiences of this process form an internal working model of attachment (Bowlby, 1973). This internal working model contains not only representations of others but also of the self: generally, a child whose parents are responsive and caring will develop an internal working model of being loveable and valuable, whereas a child whose parents are inconsistent or hostile will develop an internal working model of being unworthy and defective. One’s internal working model of attachment is thought to influence how relationships are approached later in life. Further developments in attachment theory have included attempts to classify patterns of attachment behaviour as being secure, insecure avoidant, insecure ambivalent (Ainsworth et al., 1978) with an additional category of disorganised being later added (Main & Solomon, 1986). Research has also found that having emotionally supportive relationships in later life can enable people whose attachment style was originally insecure to develop an earned secure attachment (Saunders et al., 2011). A recent meta-analysis of 224 studies concluded that having a secure attachment style in adulthood is associated with a number of positive mental health outcomes (Zhang et al., 2022).

Attachment theory may have some explanatory role in the link between traumatic events and psychological distress, given how many of the experiences that are considered to be traumatic have an interpersonal dimension. Firstly, early experiences of abuse and neglect will impact on the quality of attachment relationship and internal working model developed by the child (Breidenstine et al., 2011). Additionally, there is evidence to suggest that those without a secure attachment may experience higher levels of distress when faced with traumatic events (Woodhouse et al., 2015). Attachment theory may be particularly pertinent when considering the impact of trauma on people with a learning disability because of additional challenges in developing secure attachment. Parents may go through a grieving process for their imagined ‘perfect child’ upon receiving the news that their child has a learning disability (Goldberg et al., 1995) which may affect their ability to be responsive to their child’s needs. Additionally, children with a learning disability may initiate fewer interactions and make signals that are more difficult for parents to understand and respond effectively to (Fletcher, 2016). People with a learning disability may continue to face additional challenges in maintaining supportive attachment relationships later in life because of factors such as high staff turnover and care placements that are far from home.

The Power Threat Meaning Framework

The Power Threat Meaning Framework was developed as a conceptual alternative to functional psychiatric diagnosis in the understanding of emotional distress, unusual experiences and troubling behaviour (Johnstone & Boyle, 2018). It aims to reframe what might be thought of as ‘symptoms’ as meaningful responses that allow people to survive in conditions of adversity. The Power Threat Meaning Framework asks ‘what has happened to you?’ or ‘how has power operated in your life?’ This may be particularly pertinent for people with a learning disability, who generally have more negative experiences of power operating in their lives than other people. For instance, abuse can be considered the (mis)use of interpersonal power; legal power may have operated in people’s lives through institutionalisation and use of the Mental Health Act and Mental Capacity Act; and ideological power in the form of societal discourses about the value of those with a learning disability may act to undermine and silence people. The Power Threat Meaning Framework describes how these experiences may pose a number of threats to people, for instance to their physical safety or self-esteem, and so people may employ ‘threat responses’ to aid survival. The meaning that someone makes of experiences of power and threat, and the resources available to a person mediates the kinds of threat responses they may use to survive the situation. The fewer opportunities afforded to people with a learning disability to make meaning and have control over their lives may narrow the number of threat responses available, perhaps going someway to explain why people with a learning disability may be more likely to show aggression or self-injurious behaviour in response to trauma.

Summary and conclusion

Thus far, consideration has been given to how learning disability and trauma can be defined, and how trauma impacts on the lives of people with a learning disability. The extent of the issue suggests an urgent need for health and social care services supporting people with a learning disability to be sensitive and responsive to the impact of trauma, in line with the TIAs outlined above (Goad, 2022; Keesler, 2014a; Learning Disability Professional Senate, 2019). This is given further consideration below, through the means of a systematic literature review.

Systematic literature review: How can health and social care services respond effectively to people with a learning disability who are impacted by trauma?

Design

The aim of the systematic review was to explore how health and social care services can respond effectively to people with a learning disability who are impacted by trauma. A qualitative synthesis was considered most appropriate to address this aim in order to capture the nuances and complexities of the subject at hand (Flemming & Noyes, 2021). It was hoped that by synthesising the perspectives of multiple stakeholders, aspects of service response that are helpful as well as barriers to providing such responses could be identified, in order to make recommendations for future research as well as policy and practice. This is the first time this topic has been the subject of a qualitative evidence synthesis, as confirmed by searching PROSPERO, Cochrane Library and Journal of Systematic Reviews.

The qualitative evidence review was conducted by a sole researcher to conform to the academic requirements of her programme. The details of the search strategy and method of synthesis are reported on in detail below with the aim of demonstrating the rigour of the review (Tong et al., 2012).

Search strategy

In order to develop a search strategy, the aim of the review was considered with reference to the SPIDER framework (Sample, Phenomenon of Interest, Design, Evaluation, Research; Cooke et al., 2012), which was designed to aid with the structure of qualitative research questions. Preliminary searches were initially carried out before the final search terms were arrived on in order to explore how different terms were used in the literature. For instance, it was observed that some articles that are concerned with trauma focus on trauma related to abuse specifically, and use the terms interchangeably; therefore, abuse was included as an alternative term for trauma. The following search terms were arrived upon:

1) Learning disabilit* OR intellectual disabilit* OR developmental disabilit*

2) Trauma OR abuse OR adverse childhood experiences

3) Response OR care OR service OR support OR treatment

4) Qualitative OR interview OR focus group

5) #1 AND #2 AND #3 AND #4.

The above search terms were then used in an electronic search of the databases CINAHL, Medline, APA PsycArticles and APA PsycInfo in September 2023. Truncation and Boolean operators were used in the search in order to maximise the likelihood of retrieving articles addressing the aims of the review and meeting the below detailed inclusion criteria.

Article inclusion and exclusion criteria

The inclusion criteria were as follows. Articles which a) explore how health and social care services respond to adults with a learning disability who are impacted by trauma b) utilise qualitative methods c) were published in the English language and d) were peer reviewed were selected for inclusion. The decision to exclude articles published in languages other than English was made as resources for translation were not available. Inclusion was limited to peer reviewed articles to provide some metric of quality and this is given further consideration below.

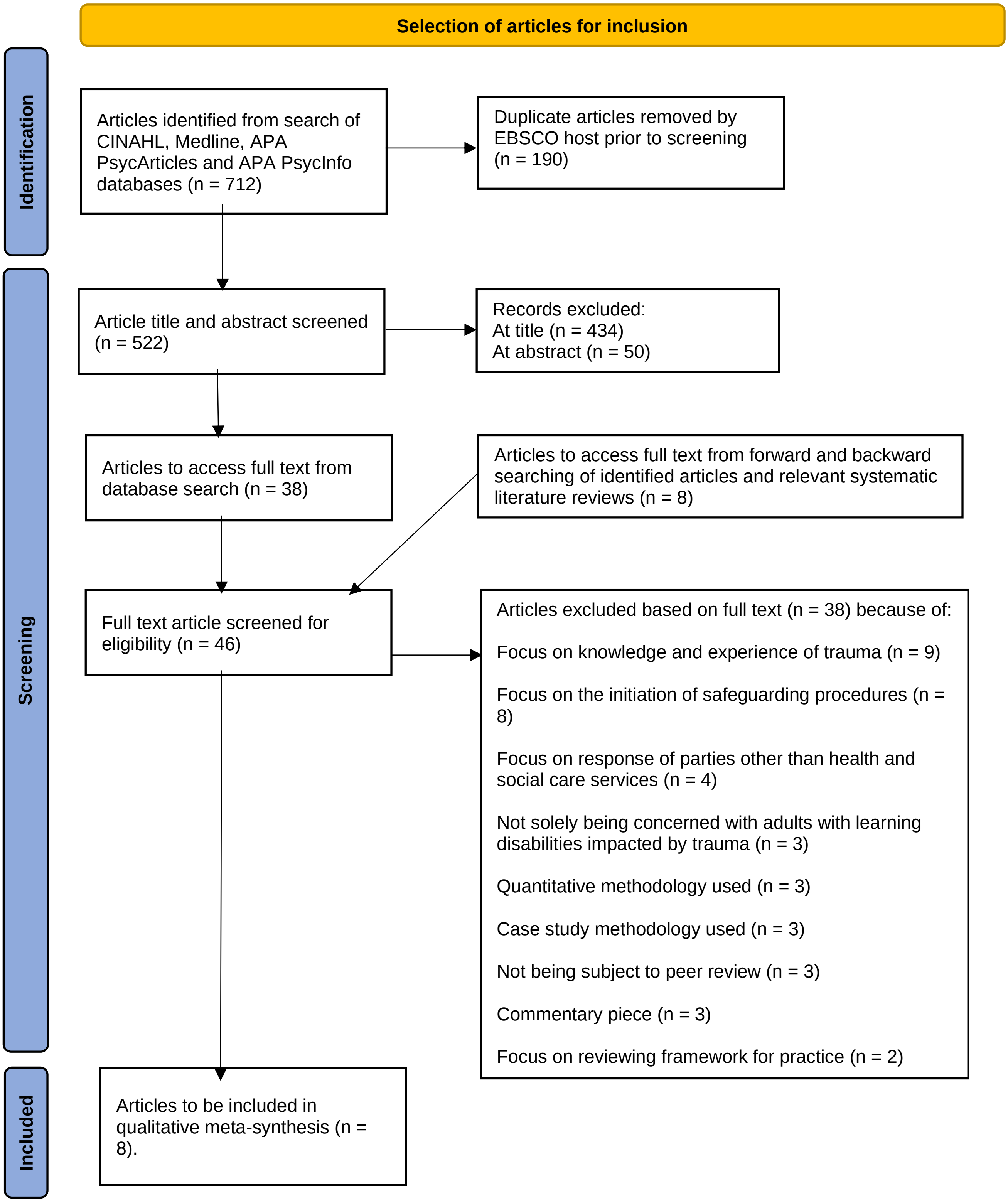
Articles were excluded on the basis of being a) concerned solely with knowledge and experiences of trauma or abuse rather than service response b) concerned solely with an immediate response to traumatic events (eg initiation of safeguarding procedures after abuse) rather the impact of these events c) concerned with response to children and young people with a learning disability, given the differences in service provision d) concerned with the response of parties other than health and social care services, such family, police and courts to issues of trauma e) concerned with evaluating specific assessments or interventions for trauma or f) reflective or commentary pieces.

Article screening and selection

A total of 712 results were yielded from the initial electronic search, of which 190 were removed by EBSCO host due to being duplicate results. Article titles and abstracts were screened against the above outlined inclusion and exclusion criteria. 434 articles were excluded from the title and 50 from the abstract. This left 38 articles which appeared likely to meet the inclusion criteria, the full texts of which were then accessed and further examined against these criteria. A total of seven articles were selected for inclusion in the qualitative synthesis through this process (Fraser-Barbour et al., 2018; Keesler, 2014b; Keesler, 2016; McNally et al., 2022; O’Malley et al., 2020; O’Malley et al., 2019; Truesdale et al., 2019). The reference lists and lists of articles that cited these studies, and three relevant review articles (Cook & Hole, 2021; McGilloway et al., 2020; McNally et al., 2021) were then screened in order to identify further relevant articles. A further article was identified for inclusion through this process (Kildahl et al., 2020a), giving a total of eight studies. Figure 1 below provides an overview of how articles were screened out at each stage.

Figure 1

PRISMA (2020; in Page et al., 2021) flow chart for article inclusion.



Data extraction and synthesis

The selected articles were synthesised using thematic synthesis (Thomas & Harden, 2008), an approach developed from Braun and Clark's (2006) thematic analysis. Thematic synthesis was selected as it can be used with relatively 'thin' data as opposed to other approaches such as meta-ethnography (Flemming & Noyes, 2021) and some of the findings of the included studies could not be considered particularly rich. The initial stage was to extract the data to be synthesised from the articles. In qualitative synthesis what is considered to be 'data' or 'findings' is subject to some debate. Sandelowski and Barroso (2002) express the importance of distinguishing the two, however reporting styles vary with some authors relying more heavily on the use of data in the form of direct quotes to elucidate their argument in order to allow participants to 'speak for themselves'. As such, Thomas and Harden (2008) described difficulties in identifying key concepts and succinct findings and therefore extracted all text under 'results' or 'findings' headings. This approach was followed in the present meta-synthesis.

Once the findings were extracted, line-by-line coding took place to capture the meaning and content of each sentence, with some sentences being assigned more than one code. Once the coding was completed, it was examined for consistency across the articles, with codes holding similar meanings being merged. Next, the codes were grouped to develop descriptive themes. From these descriptive themes, analytic themes were generated with the aim of 'going beyond' the findings of the original articles to create a narrative as to how services might respond effectively to people with a learning disability who are impacted by trauma, in line with the aims of the synthesis.

Reflexivity

It is recognised that there is a need for those conducting thematic synthesis to consider their own position on the subject at hand, due to the interpretive nature of qualitative evidence synthesis (Bearman & Dawson, 2013). In relation to the topic of the current review, the researcher who is a Trainee Clinical Psychologist who has worked with adults with a learning disability who were impacted by trauma in community, residential and hospital settings. This has included services specifically for those with a learning disability and mainstream services. While deliberating the below synthesis, the researcher considered her own perspectives on what has worked well and what has not in her experiences of supporting this group.

Findings

Table 1 below details the key characteristics of each study. A total of 116 participants were included in the original studies. These included direct care staff, clinical psychologists, psychiatrists, nurses, care/service coordinators and managers working across various health and social care settings, such as psychiatric hospitals, community learning disability services, mainstream sexual violence services, residential accommodation and day centres. Two people with a learning disability were interviewed alongside staff by O’Malley et al. (2019). The included studies took place in five different countries – the UK, USA, Ireland, Norway and Australia.

Table 1

Key characteristics of the included studies.

Author	Purpose	Setting	Sample	Data collection	Outcome
Fraser-Barbour (2018)	To explore service providers perspectives on what is helpful for people with a learning disability who have experienced sexual violence	Australia	7 professionals working in either disability or sexual violence services, including 2 support workers; 3 care coordinators and 2 policy officers	Interview	Five themes were generated around what facilitates or hinders professionals working with people with a learning disability who have experienced sexual violence: *connecting clients with services and establishing a rapport; access to information about histories of trauma; policy context; inaccessibility and unavailability of mainstream violence response services; client understanding of what happens "next" after identification of harm.*
Keesler, 2014b	To explore service coordinators' understanding of people with learning disability's experiences of adverse life events, trauma, and related services.	USA	15 service coordinators working in human service organisations	Interview	Three themes were generated around the experiences and needs of people with a learning disability who have been impacted by trauma encountered by service coordinators in their roles – *experiencing adversity, responding to adversity and adapting to adversity.*

Keesler, 2016	To explore staff perceptions, understanding and experiences of trauma and trauma informed care for people with a learning disability	USA	20 members of staff working in a trauma informed day programme, including direct care, nursing, administrative and managerial staff	Interview	Staff experiences with trauma informed care for people with a learning disability were explored with reference to its key principles. Factors that made providing effective support challenging were identified at multiple levels including those related to people with a learning disability, staff, management and organisational contexts.
Kildahl et al., 2020a	To explore clinicians' retrospective perceptions of failure to detect sexual abuse in a young man with a learning disability and Autism Spectrum Disorder	Norway	5 clinicians working in an inpatient psychiatric ward, including 3 nurses, 1 clinical psychologist and 1 psychiatrist	Interview	Three themes were generated around staff's perceptions of becoming aware an individual they cared for was affected by abuse: *We did not consider trauma and abuse, and we did not ask him; He tried to tell us – indirectly; Possible signs of abuse were attributed to ASD or depression*
McNally et al., 2022	To explore the understanding of trauma, trauma interventions and trauma informed care among staff working into community residential services for adults with a learning disability	UK	32 staff working in community residential services including 8 direct care staff, 11 managers and 13 specialist practitioners	Interview	Analysis identified some differences between staff groups in their understanding of key principles of trauma informed care and effective support for people with a learning disability who were impacted by trauma. It was concluded however that all staff would benefit from further support and training to improve their ability to recognise and respond to trauma

O'Malley et al. (2020)	To explore clinical psychologists' experiences of working with people with a learning disability who have experienced sexual violence	Ireland	6 clinical psychologists working in learning disability services.	Interview	Five themes were generated around clinical psychologists' experiences of working with people with a learning disability who had experienced sexual violence: *therapeutic adaptations and creativity; invalidation and exclusion; too many "catch all" approaches; absence of supports; mixed attitudes in approaching abuse*
O'Malley et al. (2019)	To investigate what supports may be available for people with a learning disability who have experienced sexual violence and whether they are helpful	Ireland	2 people with a learning disability, 2 support staff and 2 clinical psychologists, accessing or working in a community learning disability service	Interview	Six themes were generated around important factors to consider in supporting people with a learning disability who were impacted by sexual violence: *novel and innovative practice; complex multifacted abuse; "hush-hush" attitudes; suggestibility; confidence and control; alliances.*
Truesdale et al., 2019	To explore the views of learning disability health care professionals on service provision for people with a learning disability and traumatic stress.	UK	25 clinicians working in learning disability services including 7 clinical psychologists, 6 psychiatrists, 6 nurses and 6 allied health professionals/social workers.	Interview	Seven themes were generated around effective support for people with a learning disability affected by trauma: *unmasked trauma; trauma informed care; person-centred care and support; multi-disciplinary working; reasonable adjustments; barriers to treatment; awareness, training and education*

Quality appraisal

The eight identified articles were subject to quality appraisal using the Critical Appraisal Skills Programme (CASP) Checklist for Qualitative Research (Critical Appraisal Skills Programme, 2018). The CASP checklist outlines 10 areas for consideration when assessing the quality of research and invites the reviewer to make a judgment as to whether each area has been sufficiently addressed, recording a response as ‘yes’, ‘no’ or ‘can’t tell’. The CASP checklist does not include a scoring system, but it can be used to make an assessment of whether the article’s quality can be considered low, moderate or high (Long et al., 2020). According to these standards, there was some variation in the quality of the reviewed articles. Only one included article (O’Malley et al., 2019) was deemed to have sufficiently addressed all the areas included on the CASP checklist and was subsequently rated as being of high quality. The other articles were deemed to be of moderate quality because each had several areas where there was insufficient detail reported to decisively state whether that particular criteria had been met, although other areas of strength were identified. A table detailing the ratings for each article and how they were arrived upon can be found in Appendix A.

Generally, the articles outlined their aims and findings clearly, and the majority addressed the implications for their research, with the exception of Keesler (2014b) and Keesler (2016), although this may have been because the articles were both part of the same larger project. General areas of limitation across the articles were the level of discussion of ethical issues and the impact of the researcher on the data collection and analysis, with some papers giving little more than a cursory mention that these issues had been considered. A notable exception to this was O’Malley et al. (2019), perhaps because the inclusion of people with a learning disability as a potentially vulnerable participant group meant that greater scrutiny was given to these matters. Given that there is no consensus about the use of quality appraisal in systematic reviews (Cahill et al., 2018) and the question has been raised as to whether the CASP checklist assesses quality of methodology independent of quality of reporting (Long et al., 2020), no articles were excluded on the basis of the quality appraisal. This was additionally considered a favourable course of action given the relative paucity of research in this area.

Results of the thematic synthesis

From the reviewed articles, four themes were generated to convey an understanding of how people with a learning disability who are impacted by trauma can be effectively supported. The themes were: *Applying the trauma lens; Creating a person-centred intervention; Healing happens in collaborative contexts* (split further into two subthemes of *No matter what – the therapeutic relationship is key* and *Everyone needs to work together);* and *Doing no harm.* Whether these themes were deemed to be present across the eight articles is represented in Table 2 below.

Table 2

Presence of the generated themes across the included articles

	Fraser-Barbour (2018)	Keesler, 2014b	Keesler, 2016	Kildahl et al., 2020a	McNally et al., 2022	O'Malley et al. (2020)	O'Malley et al. (2019)	Truesdale et al., 2019
Applying the trauma lens	√	√	√	√	√	√	√	√
Creating a person-centred intervention	√	√	√		√	√	√	√
Healing happens in collaborative contexts	√	√	√		√	√	√	√
No matter what – the therapeutic relationship is key	√	√	√		√	√	√	
Everyone needs to work together	√	√	√		√	√	√	√
Doing no harm	√	√	√	√	√	√	√	√

Theme One – Applying the trauma lens

The theme of applying the trauma lens refers to an important first step in responding effectively to people with a learning disability who are affected by trauma, of acknowledging and recognising its impact. This theme also describes some of the challenges health and social care staff may encounter in doing this.

A variety of events were referred to as being traumatic, with sexual abuse being the most commonly represented in the reviewed literature (Fraser-Barbour et al., 2018; Kildahl et al., 2020a; O'Malley et al., 2020; O'Malley et al., 2019). Other traumatic experiences mentioned included physical and psychological abuse; loss of caregiver; exposure to family conflict and institutionalisation (Keesler, 2014b; Keesler, 2016). Some participants conveyed that any event could be considered traumatic, depending on the individuals' subjective experience of it, and that this may be affected by someone having a learning disability (Keesler, 2016; McNally et al., 2022; O'Malley et al., 2019). Throughout the reviewed literature there was acknowledgement that people with a learning disability are more likely to be exposed to traumatic experiences, and a view that when they are exposed, they may be more severely affected due to having fewer coping mechanisms and social supports available to them (Keesler, 2014b; Keesler, 2016; McNally et al., 2022).

The impact of trauma was considered to be wide-ranging. Trauma was perceived as manifesting in psychological distress, both in terms of 'classic' post-traumatic stress responses such as flashbacks and nightmares (McNally et al., 2022; O'Malley et al., 2019) and more generally in increased anger, fear or sadness (Keesler, 2014b; Keesler, 2016; Kildahl et al., 2020a; McNally et al., 2022). Trauma was also conceptualised as negatively impacting on individuals' physical health (McNally et al., 2022) and interpersonal relationships (Keesler, 2014b; McNally et al., 2022; O’Malley et al., 2019). In the reviewed articles the most prominent attribute understood to be indicative of trauma amongst people with a learning disability was behavioural presentations, such as self-injury, aggression or ‘acting out’ of past events (Keesler, 2014b; Keesler, 2016; Kildahl et al., 2020a; McNally et al., 2022). However, in practice this link was often reported to be obscured, with the behavioural manifestations of trauma being conceptualised as ‘challenging behaviour’, consequential to the learning disability itself (Fraser-Barbour, 2018; O’Malley et al., 2020; Truesdale et al., 2019), Diagnostic overshadowing of the impact of trauma was also sometimes reported with regards to an associated neurodevelopmental or mental health condition. The following quote is illustrative of this: “He had quite a few symptoms. We understood them differently, but they probably were associated with trauma. We were too quick to find an explanation. I think we explained too much by his autism” (Kildahl et al., 2020a, p.198).

Despite the consensus amongst professionals that people with a learning disability are disproportionately likely to be impacted by trauma, in practice it was often overlooked (Keesler, 2014b; Kildahl et al., 2020a; McNally et al., 2022; O'Malley et al., 2020; O'Malley et al., 2019; Truesdale et al., 2019). The above quote also illustrates how information about the incidences of trauma coming to light led to professionals re-evaluating the meaning they attributed to people’s behaviour (Fraser-Barbour, 2018; Kildahl et al., 2020a; O’Malley et al., 2020; Truesdale et al., 2019). This suggests that having access to people's histories is important in order for health and social care services to respond effectively to people with a learning disability who are impacted by trauma. A number of challenges around this were identified in the reviewed literature. There was often a reliance on verbal disclosure for trauma to become known, and there was uncertainty as to how this barrier could be addressed for the proportion of people with a learning disability who do not have the language skills required to articulate what has happened to them (Fraser-Barbour, 2018; Keesler, 2014b; Kildahl et al., 2020a; McNally et al., 2022; Truesdale et al., 2019). This dilemma was summarised by a participant in Fraser-Barbour's (2018) study:

> It might be really difficult because some people with intellectual disabilities might be non-verbal, so that would be – I don't really know how they would be able to disclose it in that case. That would be really hard and I wouldn't really know how to go about finding out […] If they were non-verbal, I wouldn't really know how to check or ask (Fraser-Barbour, 2018, p.211).

There was sometimes also a reluctance to ask people who might be able to disclose for fear of upsetting people (Kildahl et al., 2020a). As people travelled through service provision, information about histories of trauma were not always shared. There appeared to be a tension here between not sharing information in order to respect people's privacy but this consequently limiting staff's ability to address people's needs (Fraser-Barbour, 2018), and perhaps also being indicative of a "hush-hush" culture around abuse (O'Malley et al., 2019, p.111).

These challenges mean that health and social care staff are not unlikely to be supporting people with a learning disability who are affected by trauma without being aware of it. Applying the trauma lens may help staff to think about the potential impact of hidden trauma on those they support, although caution must be taken to not make false assumptions about people's histories or rely on stereotypes (Kildahl et al., 2020a; McNally et al., 2022).

Theme Two – Creating a person-centred intervention

Linking with Theme One which details the wide-ranging and often long-lasting ways trauma can impact on the lives of people with a learning disability, this theme addresses the need for intervention arising from this and what interventions were considered to be beneficial. This theme also gives consideration to how any support provided can best meet the specific needs of people with a learning disability.

While there appeared to be a consensus across all the reviewed articles that intervention beyond the usual care was required for people with a learning disability who are impacted by trauma, there were differences in the types of interventions that were cited as effective. For example, participants in several articles report that psychiatric medication ameliorated the distress people experienced as a result of trauma (Keesler, 2014b; McNally et al., 2022; O'Malley et al., 2019) however there were concerns raised elsewhere that use of medication constituted restrictive practice and was therefore incompatible with trauma informed approaches (Keesler, 2016). Similarly, behavioural approaches that focus on adjusting environmental contingencies associated with 'challenging behaviour' were seen by some as helpful (Fraser-Barbour, 2018; Keesler, 2014b), while others concluded the efficacy of such approaches is limited in addressing behaviours related to historic trauma as they primarily focus on the here and now environment (O'Malley et al., 2020).

There was a particular emphasis on the provision of psychological therapy across the sample, with modalities including EMDR; CBT and its third-wave iterations; psychodynamic psychotherapy; person-centred therapy; eidetic psychotherapy; systemic family therapy and creative therapies being specifically mentioned as being helpful (Fraser-Barbour, 2018; Keesler, 2014b; O'Malley et al., 2020; O'Malley et al., 2019; McNally et al., 2022; Truesdale et al., 2019). There was some concern however that therapy could cause people more distress, particularly when it involved revisiting painful memories (O'Malley et al., 2019) and that it did not always seem to make a difference to people overall. This was sometimes attributed to factors relating to the person such as avoidance or lack of motivation to engage (Keesler, 2014b) or the severity of their learning disability (Truesdale et al., 2019).

The success of any therapy was seen as being reliant on adaptations being made to the intervention to account for the difficulties associated with the person's learning disability (Fraser-Barbour, 2018; O'Malley et al., 2020; O'Malley et al., 2019; Truesdale et al., 2019). These included placing less emphasis on higher order cognitive processes and verbal communication in sessions (O'Malley et al., 2019) and employing creative means to explore past events (O'Malley et al., 2020). The following quote from a clinical psychologist interviewed by Truesdale et al. (2019) gives some examples:

> With exposure we would use maybe drawings instead of writing. Imagining is very difficult for some individuals so often it's the use of story or puppets, or just being imaginative. The therapists have to be quite imaginative, to find a way for the person to be able to, not only tell their story, but to re-enact some bits of it at times... (Truesdale et al., 2019, p.1440).

Flexibility to offer shorter sessions and see people for longer periods of time was also considered beneficial (Truesdale et al., 2019), although some psychologists felt that brief interventions could sometimes be sufficient in some cases (O'Malley et al., 2020; O'Malley et al., 2019). It was emphasised that there is no single set of adaptations suitable for all people with a learning disability and that any intervention (psychological therapy or otherwise) had to tailored to the particular individual (Keesler, 2016; O'Malley et al., 2020; Truesdale et al., 2019), with one clinical psychologist summarising that "Every individual who walks in the therapeutic session is a different person altogether. So it is a very creative work." (O'Malley et al., 2020, p.61).

A common dilemma throughout the reviewed articles was where people could go to receive such an individualised intervention. Learning disability services were perceived as being better at adapting to people's communication needs than mainstream trauma services (Fraser-Barbour, 2018). However, given that learning disability services were designed to provide input for people with a learning disability around a number of health issues, there was a sense that difficulties relating to trauma were sometimes seen as a niche or peripheral area of practice requiring external specialist support (McNally et al., 2022; O'Malley et al., 2020). This suggests a real risk of people with a learning disability falling through gaps in service provision or receiving a service that only partially meets their needs, contrary to the identified need for a person-centred approach. This also suggests a need for collaboration between services with different scopes of practice, linking to the third theme.

Theme Three - Healing happens in collaborative contexts

This theme captures the sense in the reviewed articles that collaboration and connection between people is crucial for people with a learning disability who are impacted by trauma to be supported well. It is divided into two subthemes – *No matter what – the therapeutic relationship is key* and *Everyone needs to work together.* The former refers to the relationship between individuals with a learning disability and health and social care staff and the latter focuses on collaboration and support between staff.

No matter what - the therapeutic relationship is key

Creating safe, trusting relationships between people with a learning disability and health and social care staff was considered a priority, without which any therapeutic intervention was unlikely to be effective (Fraser-Barbour, 2018; Keesler, 2014b; Keesler, 2016; O'Malley et al., 2020; O'Malley et al., 2019; McNally et al., 2022). Capturing this, one psychologist stated “No matter what model you throw out there it’s the relationship. Em… It’s the trust. It’s the boundaries that hold the person. It’s the being there from week in to week out.” (O’Malley et al., 2020, p.61).

Building safe relationships was also acknowledged to be crucial for care/support workers, who were not providing any targeted intervention as such, but were key in supporting people day to day (McNally et al., 2022). Specifically, it was important for staff to be consistent and reliable (Keesler, 2014b; O’Malley et al., 2020) and to be validating of the individuals’ experience (O’Malley et al., 2020). Safe relationships were also characterised by an awareness of the power imbalance between people with learning disabilities and professionals and attempts to promote people’s autonomy (Keesler, 2016; O'Malley et al., 2020; O'Malley et al., 2019).

There was some acknowledgement that navigating relationships with people who have been impacted by trauma can be challenging, as people may find it more difficult to trust others and recreate unhealthy relational patterns with staff (Keesler, 2016; O'Malley et al., 2020; O'Malley et al., 2019; McNally et al., 2022). This following quote from one of Keesler’s (2016) participants articulates this and the resulting need for staff working with traumatised people to be supported, linking with the next subtheme:

> Without trust you don’t have any of this... we are dealing with individuals that can be very explosive... So if you don’t trust your co-worker or your management then you are setting yourself up for failure... Staff is here for each other... we are all there for the individuals... so that we can build trust because [the individuals] haven’t learned to trust anybody throughout their life (Keesler, 2016, p.487).

Everyone needs to work together

Working with people with a learning disability who are impacted by trauma was acknowledged to be challenging for health and social care staff, both in terms of emotional impact and in having confidence in their ability to help people (Keesler, 2014b; Keesler, 2016; O'Malley et al., 2020; O'Malley et al., 2019; Truesdale et al., 2019). One participant working in social care interviewed by McNally et al. (2022) reflected that “the job is no longer helping people make their tea, do their shopping and going out. It’s traumatic times for staff as well because of the complex people we now expect them to care for” (McNally et al., 2022, p.1170).

Staff frequently cited access to supervision and training as being important to support them in their roles; equally, this was often reported to not be prioritised or as available as staff would like (Fraser-Barbour, 2018; Keesler, 2014b; Keesler, 2016; McNally et al., 2022; O'Malley et al., 2020; O'Malley et al., 2019; Truesdale et al., 2019). As aforementioned, the impact of trauma on people with a learning disability was to some extent considered a niche and peripheral area of practice, meaning there were a lack of evidence-based guidelines on how to support people which some professionals saw as hampering their work (O'Malley et al., 2020; O'Malley et al., 2019; Truesdale et al., 2019).

A lack of consensus as to how best to support people may have at times contributed to different approaches being taken in different parts of people's care. One participant interviewed by Keesler (2016) remarked that the difference in service philosophy between one person's day centre and residential home was "like a divorced family" (Keesler, 2016, p.488), leading to confusion and inconsistency for the individual involved. It was considered optimal for professionals from different disciplines to work together to create a unified approach to support people (Fraser-Barbour, 2018; Keesler, 2014b; Keesler, 2016; O'Malley et al., 2020; O'Malley et al., 2019) Truesdale et al., 2019). A positive example of this was support staff who worked with people on a day-to-day basis reinforcing the content of individual's psychological therapy (O'Malley et al., 2020; O'Malley et al., 2019).

Theme Four - Doing no harm

This theme refers to the need to avoid causing further harm to people with a learning disability who are impacted by trauma when supporting them. It also captures some of the difficulties staff have in preventing further harm from happening given the wider context of marginalisation of people with a learning disability.

There was an awareness of a potential for services to be a source of trauma for people. For example, one participant interviewed by Keesler (2016) observed:

> The effects of being institutionalised are so easy to see in them. They will come at you with their arms already in the pose for a [restraint]… You don't even have to do anything to put them in an intervention which is sad to me that that is their automatic response (Keesler, 2016, p.485).

This awareness led staff to consider it important to seek out alternatives to the use of restrictive practices (Keesler, 2014b; Keesler, 2016; McNally et al., 2022). In line with the importance stressed above about the power of relationships, some articles highlighted how poorly managed dynamics between people, particularly around endings could represent a re-traumatising experience for someone with a learning disability and a history of interpersonal trauma (O’Malley et al., 2020). Conditions in services at times made it more challenging to avoid difficulties around this however, with high staff turnover and vacancies undermining attempts to provide consistent relational care (Fraser-Barbour, 2018; Keesler, 2016; Truesdale et al., 2019). This may have been particularly detrimental for the many people with a learning disability who do not have relationships beyond those with paid service providers (Keesler, 2014b; O’Malley et al., 2019). Further issues around re-traumatisation were identified in regards to people’s living environments, with some people having to remain living with people who had perpetrated abuse against them (Fraser-Barbour, 2018; O’Malley et al., 2020). This particular example appears likely to undermine any other efforts to provide care and support related to the trauma.

That people were not able to leave environments where they had been abused until they had received the necessary funding and approval for a move could also be considered illustrative of a wider issue of people with a learning disability having little power and control over their own lives. Similarly, it was noted that often people with a learning disability are abused by those upon whom they are reliant on for care and protection (Fraser-Barbour, 2018; Keesler, 2014b; McNally et al., 2022; O’Malley et al., 2020; O’Malley et al., 2019), making it particularly difficult for them to resist mistreatment as “People with ID tend to be quite aware of the power differentials.

You know – they'll want to agree; they'll want to keep the system going. They'll want to do what they're supposed to do." (O'Malley et al., 2020, p. 64).

This again highlights the need for professionals to be able to recognise the impact of trauma, as the circumstances engendering it may in fact be ongoing with the affected person unable to take action to address the situation (Keesler, 2014b; Kildahl et al., 2020a). Given that it is recognised that autonomy is helpful for people to recover from the effects of trauma, it may be that the same context of disempowerment and marginalisation that makes people with a learning disability more likely to be exposed to trauma also hinders their ability to heal from it.

Discussion

Summary of findings and links to previous literature

This systematic review aimed to synthesise the available qualitative literature on the subject of health and social care services' response to people with a learning disability who are impacted by trauma, in order to explore how this group might be effectively supported. Four themes were generated using Thomas and Harden's (2008) thematic synthesis. The first theme, A*pplying the trauma lens* refers to the urgent need for those working with people with a learning disability to be able to recognise the impact of trauma, including on those who are not able to relate their experiences verbally. The second theme, *Creating a person-centred intervention* is concerned with the need for adaptations to be made to interventions in order to account for the difficulties in understanding and communicating associated with someone's learning disability. The third theme of *Healing happens in collaborative contexts* highlights the importance of relationships between people after trauma, both between staff and people with a learning disability (detailed in the subtheme of

No matter what – the therapeutic relationship is key) and between professionals in order for their work to be supported and scaffolded *(*explored through the subtheme of *Everyone needs to work together).* The fourth and final theme, *Doing no harm,* asserts the need for staff to avoid providing care that is re-traumatising, and how challenging this might be in a world that treats people with a learning disability as ‘less than’.

This evidence provided by this novel synthesis is valuable given the above-described prevalence of potentially traumatic experiences amongst people with a learning disability (Hughes et al., 2012; Jones et al., 2012; Tomsa et al., 2021) and the issue highlighted within the synthesis itself of an uncertainty amongst health and social care staff in how people with a learning disability who are impacted by trauma might best be supported. The results of this synthesis, which highlight the importance of being able to recognise the impact of trauma, prioritise safe and trusting relationships and avoid re-traumatisation, are consistent with the principles of TIAs (Huang et al., 2014; Sweeney et al., 2016; Sweeney et al., 2018),thus championing their applicability to learning disability services.

The synthesis brought together the perspectives of multiple stakeholders, the overwhelming majority of which were health and social care professionals. It is notable that out of 116 participants in eight studies, only two were people with a learning disability (in O’Malley et al., 2019). This relative lack of representation is likely to be because of ethical concerns around including people with a learning disability in research, such as ensuring people have capacity to consent and are not subject to coercion (Goldsmith & Skirton, 2015). However, it can conversely be considered that making blanket decisions to exclude entire groups of people from research participation in order to avoid coercion can be disempowering in itself as people's perspectives on their own lives are not afforded the same status as those of others (Juritzen et al., 2011). It seems crucial therefore that future research seeks the perspectives of people with a learning disability who are impacted by trauma themselves.

Moreover, the general paucity of research in this area meant that the synthesis could not be narrowed down to focus on studies conducted in a single geographical location. The five countries represented in the synthesis may have had very different arrangements for health and social care services and these local nuances may have been lost. Additionally, the majority of studies (with the exceptions of Keesler, 2014b and O'Malley et al., 2020) interviewed staff from different professional groups and did not delineate their responses. More research that focuses on particular professional groups may therefore be warranted to capture the specificities of various disciplines' role in supporting people with a learning disability who are affected by trauma.

Other potential limitations of the review are that it was carried out by a sole researcher and was limited to articles published in the English language due to time and resource constraints posed by the conditions under which the review was carried out. That this and the overall method of analysis are reported on transparently may enhance the quality of the synthesis however (Tong et al., 2012).

In conclusion, this synthesis goes some way to evidence what good practice might look like with regards to how health and social care services support people with a learning disability who are impacted by trauma. It also highlights some of the challenges health and social care staff face in attempting to meet the needs of this group and the importance of further research in this area.

Rationale for the present study

The rationale for the present study has been developed in line with the identified need for further research as to how people with a learning disability who are impacted by trauma can be best supported. It will specifically focus on the perspectives of care/support workers employed in residential settings. While this group have been included in previous research on the subject (McNally et al., 2022; O'Malley et al., 2019) their perspectives have not been separated from other professionals, which may be problematic given the vast differences in experience and training between care/support workers and other professionals such as clinical psychologists. Additionally, there is scope for further qualitative research on the perspectives of care/support workers employed in residential settings as the method of analysis used in some of the existing literature (for instance framework analysis in McNally et al., 2022) has not resulted in a particularly in-depth exploration of care/support workers' experiences.

Aims and objectives

The following aim, to be investigated through the use of qualitative methods, was arrived upon for the present research project:

- How do residential care/support workers respond to and support people with a learning disability who are impacted by trauma, or who have disclosed or been identified as having had difficult life events?

The study will attempt to explore the experiences of residential care/support workers who have worked with people with a learning disability who are impacted by trauma or difficult life events. It is hoped that by exploring this, current areas of good practice can be identified and shared. Any challenges faced by care/support workers in effectively supporting people with a learning disability who are impacted by trauma and any ways these challenges could potentially be addressed may also be identified. Overall, it is hoped that this research could contribute to improvements in care for people with a learning disability, as well as support for staff who work with them.

Chapter Two: Method

Chapter Summary

This chapter outlines the method of the present study. The ontological and epistemological positions as well as the researcher's own positionality with regards to the research are described, and the research procedure and method of analysis are reported on in depth. This chapter also contains consideration of ethical issues relating to the present research.

Epistemological positioning and justification of the methodology

Research within the social sciences requires consideration to be given to its philosophical underpinnings, including the ontological and epistemological positioning of the work (Malterud, 2016). Ontology is a branch of philosophy that is primarily concerned with the nature of being and what can be said to exist (Al-Saadi, 2014). Ontological positions are conceptualised as existing on a continuum, with a realist position at one end and a relativist position at the other. A realist position assumes that a singular reality exists 'out there' independent of human processes (Tebes, 2005). In contrast, a relativist position asserts that there is no singular reality that exists independent of human interpretation; rather, there are multiple co-existing realities that are socially produced (Baghramian & Coliva, 2019). Somewhere between these two poles is critical realism. Critical realism postulates that there is a reality that exists independent of human experience, however, this is not fully accessible and any observation of reality is socially mediated (Bhaskar, 2014). Critical realism is sometimes considered to bridge ontology and epistemology in that it combines a realist ontology with a constructivist epistemology (Maxwell, 2017) by assuming that there is a real world independent of our perceptions and that our knowledge of the world is a construction rather than an objective perception.

Epistemology can be defined as being concerned with the nature of knowledge and how knowledge can be generated (Al-Saadi, 2014). Various epistemological positions are conceptualised as aligning with the ontological positions described above, and coherence between epistemology, ontology and methodology is considered favourable for most research (Chamberlain et al., 2011). Typically, a positivist epistemology is underpinned by a realist ontology and assumes that a single reality exists and objective claims about this can be made through appropriate application of scientific method. It also assumes that knowledge that is value and bias free can be obtained (Park et al., 2020). At the other end of the continuum, roughly corresponding to a relativist ontology, is a constructionist epistemology which rather than assuming that language somehow represents reality, asserts that knowledge of reality is created through language (Burr, 2015). As described above, critical realism is sometimes considered to capture an epistemological position (Maxwell, 2017). A related idea is epistemological contextualism, which falls somewhere between positivism and constructionism and views knowledge as being contextually situated, partial and perspectival (Madill et al., 2000) Contextualism allows for multiple versions of reality and considers that while some accounts may not be more accurate than others, they may be more useful.

The present study adopts a qualitative methodology in line with the aim of exploring the experiences of residential care/support workers who have supported people with a learning disability who are impacted by trauma or difficult life events. Qualitative methodologies are particularly appropriate for research that aims to “delve into questions of meaning, examine institutional and social practices and processes, identify barriers and facilitators to change and discover the reasons for the success or failure of interventions" (Starks & Brown Trinidad, 2007, p. 1) as these are generally not considered to be quantifiable. Underpinning this, a critical realist position was adopted as I believe that both learning disability and trauma exist outside of my perceptions but the way that they are understood is dependent on social processes and contexts. Adopting this perspective for the present research means that the findings do not intend or claim to provide a direct representation of reality. Instead, they can be considered to represent a version of reality mediated by the contextualised experiences of the participants, and of myself, the researcher. Within this, the importance of researcher self-reflexivity is prioritised and will be further considered below. The present research is also influenced by a contextualist epistemology, and so assumes that the accounts of experience gathered for analysis may partially represent something of an underlying social reality, taking into account the context of the research and again requiring a high degree of researcher reflexivity (Madill et al., 2000).

Researcher self-reflexivity and positionality

In line with the ontological and epistemological positions outlined above, I considered it important to reflect on my own life experiences and perspectives throughout the research process. I attended to this by keeping a reflexive journal and engaging in supervision. Below is a statement of my positionality.

I am a 27-year-old White British woman who has conducted this research as part of training to be a clinical psychologist. I was drawn to pursue this career path because of significant personal experiences of distress which I have understood as being related to difficult events and circumstances in my life. I believe this specifically is what has driven my interest in trauma. After graduating from my undergraduate degree in psychology in 2019, I started a job as a support worker in a residential service for adults with a learning disability. Having previously worked in mainstream adult mental health services, my initial motivation for pursuing this role was more around gaining experience with a different population in order to strengthen my portfolio of clinical experience than it being a particular passion. However, it soon became one as I became more involved in the lives of the people I was caring for. The work I did was sometimes challenging, particularly when people were distressed and what I noticed in these times was that the predominant way that this distress was understood was largely limited to the immediate context. Even then, it appeared difficult for some of my colleagues to consider that people with a learning disability had emotional lives just like anybody else. I was often struck by the lack of curiosity about people's earlier life experiences and how documentation available described in great detail the variety of 'challenging behaviour' people engaged in while saying almost nothing of their personal histories.

The period of time I worked in residential care is notable for coinciding with the Covid-19 pandemic. I still remember the intense fear during the first months of the pandemic, of the possibility that the people I cared for would become gravely ill, and that if they did they would not be considered a priority for medical treatment given the disregard shown in society towards people with a learning disability. We were very fortunate in the service I worked in to avoid an outbreak until after everyone had been fully vaccinated, but the pandemic still affected my role as many of my colleagues chose to leave social care and people could not be recruited to replace them. I had been promoted to senior support worker, meaning I was in charge of organising the shift, and was often doing so with half the number of staff I was supposed to have. I felt I was constantly forced into making decisions that contradicted my values, as providing individualised care became an impossibility without asking staff to work through their breaks or stay late to provide it. By the time I left in June 2021, I was extremely burnt out and my predominant feeling about leaving was relief, although I also felt guilty for the impact me doing so would have on the residents and my remaining colleagues.

I was conscious while doing the current research that the strength of feeling associated with my own experiences may lead me to give more credence to accounts of being unsupported and so endeavoured to also ask participants and also consider in my analysis the possibility of positive experiences. That being said, my view would be that that these issues are widespread and I would as a socialist and feminist understand this as a consequence of a systemic undervaluing and exploitation of care staff, as well as a disregard for the value of the lives of people with a learning disability who are not seen as contributing in a capitalist society.

Training to be a clinical psychologist has deepened my understanding of the ways trauma can affect people, and has given me access to psychological theories and models to understand this, such as those outlined in my introduction. Whilst on placement I have worked with people with a learning disability who were impacted by trauma both directly through providing individual therapy and indirectly through working with their staff teams in residential care settings. In doing this I have noticed variation in how much staff have appeared to know about trauma and how sensitive they seem to be to the people they are caring for. In working with staff I have always tried to hold in mind my experiences of the challenges of care work and endeavoured to show appreciation even if I have not perceived people as always getting things ‘right’, and I hoped to also bring this to my research. In doing this I have also reflected on the trajectory of my career, as I have held both insider and outsider perspectives of the research. I was transparent with participants that I had previously been a support worker, which I hoped would make participants feel they could trust me to understand their experiences more. I was conscious however, that for me, care work was a transient role that I was ultimately doing to gain experience to move onto something else, and how this may have been perceived by participants for whom care work was more permanent. I was also aware that health and social care services are quite hierarchal and wondered about a potential power differential between myself and the participants, as I was more highly educated and better paid than the people I was interviewing.

Design

Within qualitative research, there are various methodologies and methods for data collection and analysis. The present study makes use of Reflexive Thematic Analysis in order to analyse patterns of meaning across the qualitative data set. (Braun & Clark, 2006). Unlike some qualitative approaches that are used for this purpose, such as Interpretive Phenomenological Analysis and Grounded Theory, Reflexive Thematic Analysis does not have particular ontological and epistemological positions ingrained within it (Braun & Clark, 2021). It is not however the case that Reflexive Thematic Analysis is atheoretical; rather, it is theoretically flexible. Those using Reflexive Thematic Analysis must take time to consider and make explicit their theoretical position as all research is predicated on theoretical assumptions, whether they are considered or not (Malterud, 2016). As described above, the present study is grounded in critical realism, which is commonly used to orient Reflexive Thematic Analysis (Braun & Clark, 2022).

As well as having an overarching theoretical position, Reflexive Thematic Analysis can be more experientially or critically oriented, with the former being focused on developing themes that are more grounded in the participants' meanings and the latter on the researcher's interpretive frame (Braun & Clark, 2022). The present study falls somewhere between the two in that it aimed to capture something of participants' experiences, but the mediation of this through the researcher's positioning allowed for a deeper understanding to be produced. The approach to analysis was primarily an inductive one. Of course, some pre-existing theories came to mind when analysing the data, as I have reflected upon in my self-reflexive statement, but the analysis was not specifically informed by pre-existing ideas and frameworks.

As well as allowing for the production of knowledge in a way that addresses the aim of the study, the use of Reflexive Thematic Analysis was also considered favourable because its findings can be communicated in a way that makes them readily 'actionable' (Sandelowski & Leeman, 2012). It was hoped that this would increase the likelihood of the research being able to be used to improve support for people with a learning disability and those who work with them.

Method of data collection

The primary method of data collection for the present study was interviews. The decision was made to utilise interviews rather than focus groups in order to give participants the time and space to discuss their experiences. A further advantage of using interviews over focus groups was that I could be more flexible around logistics in the hope of allowing more people to participate. I felt this was particularly important given the nature of care work generally involving shift work and working unsocial hours.

The interviews were semi-structured. An interview guide was developed (see Appendix B), structured around three main topic areas. This was done in order to give some focus to the interviews and increase the likelihood of obtaining data that addressed the objectives of the study. For each topic area, some potential prompt questions were listed under the main questions. Those questions were used flexibly to follow up on participants' responses, in order to facilitate rich, in-depth accounts of their experience. The flexible structure of the interviews allowed participants to spend time discussing what was most important to them. Another advantage was that participants' own language could be used in the follow up questions, facilitating mutual understanding.

Interview Guide

As indicated above, an interview guide with three topic areas for discussion was produced for use in the interviews. This topic guide was developed through consideration of the research aim, and the existing literature on support for people with a learning disability who are impacted by trauma. The first topic area was centred around the types of life experiences participants perceived to be traumatic or difficult, and how they were seen as impacting on the people with a learning disability they cared for. The second topic area was about how the support workers responded to people with a learning disability who were impacted by trauma, and the support and guidance that influenced how they responded. The third area was around the impact of the support provided, both in terms of the impact on the residents, and the impact on the staff providing the support. As the interviews were semi-structured, the order of the topics as presented in the guide did not need to be rigidly adhered to. However, in anticipation that participants may find it easier to discuss the people they cared for than their own personal responses to their work, questions around this were generally saved for later in the interview in order to give participants time to become more comfortable and trusting.

Sampling and recruitment strategy

A target of 12-15 participants was set, to be recruited through purposive sampling. This is within the range suggested as being appropriate for a doctoral level qualitative research project (Braun & Clark, 2013). Pre-determining an appropriate sample size is less straight forward in qualitative than quantitative research, and debates around how to ascertain whether a sample size is adequate are ongoing (Malterud et al., 2016). Malterud et al. (2016) propose that a concept of information power is used to determine what is an appropriate sample size, and outlined information power as being derived from (a) the aim of the study, (b) sample specificity, (c) use of established theory, (d) quality of dialogue, and (e) analysis strategy. The aims of the study were focused in that they were around the particular experience of supporting people with a learning disability who are impacted by trauma, rather than a broader exploration of care/support work. In line with this, the participants recruited had particular experience of this topic, on which the existing literature is sparse. According to Malterud et al. (2016) these conditions may mean that there is sufficient information power with as few as 6-10 participants. However, the inductive approach to analysis and aim of exploring commonalities across accounts may mean a higher number of participants are required to ensure information power. Of course, some of Malterud et al.’s (2016) criteria, such as quality of dialogue, could not be fully determined prior to data collection, although the consideration given to how to conduct the interviews as well as the amount of knowledge of the subject possessed by the researcher was hoped to facilitate this. Other approaches for determining sample size include examining the sample sizes used in qualitative research on similar topics (Mason, 2010). Of the articles included in the literature review described in Chapter One that used thematic analysis, sample sizes ranged from six (O'Malley et al., 2020) to 25 (Truesdale et al., 2019), perhaps reflecting the lack of consensus around appropriate sample size.

The following inclusion criteria were outlined for participation in the research:

- Employment as a care/support worker within a residential service for adults with a learning disability within the UK.
- Experience of working with at least one adult with a learning disability who was impacted by trauma or who had disclosed or been identified as having a difficult life event in this role.
- Employment in this role for at least 6 months in the past 3 years. This criteria was set in the hope that this length and recency of experience would allow for participants to provide in depth accounts of their relevant experience.
- Sufficient use of the English language to be able to discuss their experiences, due to lack of facility for translation.

Additionally, the exclusion criteria were as follows:

- Experience solely working with adults with a learning disability in non-residential settings, such as hospitals or day centres, due to the differences in role and service function.

- Experience solely gained through working in residential settings outside the UK.
- Experience solely working with children with a learning disability, as their needs and service provision may be significantly different
- Length and recency of experience contravening the above criteria
- Possession of registration as a health care professional. This was an exclusion criterion because it was considered that experiences gained in these roles may be sufficiently different to detract from the aim of the study to focus on care/support workers' perspectives.
- Insufficient fluency in English

Recruitment was one of the more challenging aspects of the research. When recruitment was opened in May 2023 the study was advertised through social media websites, such as Facebook, Twitter and Reddit, on both the personal pages of the researcher and specific forums and groups aimed at people working in health and social care. The study advert (see Appendix C) contained my contact details, and potential participants were invited to contact me via email or phone to discuss participation. I also approached former colleagues from my time working in residential care to ask if they, or someone they knew, would be interested in taking part. I also attempted to use snowball sampling by asking participants to share the research with anyone they knew who might be eligible to participate. Through discussing the research with people in my personal network, I got a sense of why people might decline to come forward or participate in the research. Potential participants would sometimes report not being aware that anyone they cared for was impacted by trauma, and felt therefore that they would not have enough to say on the matter. Additionally, one participant told me he felt his colleagues would not want to participate in the research because of difficult circumstances that were happening in that service at present.

As recruitment was slower than hoped, an amendment to my ethics application was sought in August 2023 to allow me to contact services directly and contact university courses with students who were likely to have had relevant work experience. I contacted over 50 private and third sector companies who ran residential services for people with a learning disability but only one responded to offer to circulate the research advert in their staff newsletter. I also contacted every learning disability nursing course in the UK, the majority of which did respond and agree to share my research with their students. I continued to publicise the study through social media and word of mouth until recruitment closed.

When potential participants made contact, they were provided with the study information sheet (see Appendix D) and asked to confirm whether they met the inclusion criteria for the study. If potential participants met these criteria and wanted to take part in the study, they were provided with a consent form (see Appendix E) and an interview was scheduled. Interviews were scheduled at a time that was convenient for participants. Participants who were geographically close enough for me to practically offer a face-to-face interview were given this option, along with video or telephone call. Ultimately, two interviews were conducted face-to-face and the remaining 10 were conducted by video call.

The decision was made to close recruitment at the end of February 2024 with 12 interviews completed in order to allow for sufficient time to analyse and write up the research. Of the interviews completed, two were recruited through word of mouth; two were recruited through a clinical psychologist who had seen my advert on social media; one through the mailing list of a learning disability nursing course and seven through social media. In addition to this, a further three interviews were scheduled but not completed, with two participants cancelling on the day due to a shift change and being unwell, and a further participant simply not joining the video call. None got back in touch to reschedule. Other potential eligible participants got in touch and agreed to participate but ultimately no interview could be arranged due to scheduling issues, including those related to their work such as not receiving rotas far enough in advance to be able to plan for an interview. Several other people expressed interest but were not invited to participate due to not fitting into the inclusion criteria outlined above.

Participants

12 participants took part the study. Their assigned pseudonyms are displayed in the table below, along with their length of experience working in residential settings with adults with a learning disability. Length of experience varied from six months to 16 years; the mean length of experience was six years. Although it wasn’t specifically asked, the many of the participants described having worked in other roles in health and social care, including in physical health settings, psychiatric hospitals and care settings for older people and those with dementia. Similarly, level of education was not specifically asked about, other than to ensure participants met the inclusion criteria of not holding registration as a health care professional, but many participants did share their educational histories. Six were currently pursuing or had graduated from undergraduate studies in psychology, and two were studying nursing. Others mentioned unrelated studies, meaning overall the sample was more

highly educated than care workers in general. This will be discussed further in the limitations section.

Table 3

Participant pseudonyms and length of experience working in residential care with adults with a learning disability.

Pseudonym	Length of experience
David	16 years
Omar	2 years
Freya	4 years
Teresa	5 years
Keeley	5 years
Aisha	6 months
Beth	6 years
Liam	5 years
Daniel	10 years
Kacper	2.5 years
Megan	10 years
Christopher	6 years

Other key demographics of participants are summarised in the table below at a sample level, in order to decrease the risk of participants being identifiable.

Table 4

Participant demographic information

Demographic	Category and Number of Participants (N)			
Age	20-29 (N = 5)	30-39 (N = 4)	40-49 (N = 3)	
Gender	Female (N = 6)	Male (N = 6)		
Ethnicity	White British (N = 9)	Pakistani (N = 2)	White Other (N = 1)	
Nationality	British (N = 11)	Polish (N = 1)		
Area of UK	East of England (N = 2)	South-East England (N = 2)	Midlands (N = 2)	Wales (N = 2)
	South-West England (N = 1)	Yorkshire (N = 1)	North-West England (N = 1)	Scotland (N = 1)

The participants ranged in age from 22-46 years old; the mean age at time of participation was 32.6 years old. There was an equal split between male and female participants in the sample. As indicated in the table above, the majority of participants were of White British ethnicity and were British nationals. Participants were located across the United Kingdom, although Northern Ireland was unrepresented. Participants were not asked about their socio-economic status as the sample was occupation based and this is already an indicator of socio-economic status.

Procedure

As described under recruitment, participants were provided with the study information sheet and consent form prior to the interview. On the day of the interview a recap of the most important points from the information sheet was given, particularly the potential for participant distress; where participants could seek further support if they became distressed; the likelihood that doing the interview would not directly benefit the participant; the right to decline or stop the interview at any time and confidentiality and its limits. Participants were also given the opportunity to ask any questions. The majority of participants signed the consent form prior to meeting. Those who wished to ask questions before returning the consent form did so. Once written consent had been obtained, participants were asked verbally if they were happy to start the interview before audio recording was commenced. Participants were asked some demographic questions, namely, their age, gender, ethnicity, nationality, length of experience as a care/support worker in residential care and the area of the UK they worked in, in order to contextualise the data. As described above, the interviews were semi-structured, so the questions on the interview guide were asked but not necessarily in the same order, and further questions were asked dependent on the individual participants’ answers. At the end of the interview participants were given an opportunity to add anything about their experiences they had not already discussed, before confirming they were ready for the recording to be ended. Interviews were planned to last around an hour, in order to facilitate the collection of rich, in-depth data while not being too fatiguing for either participants or the researcher. The actual duration of the interviews ranged from 54 to 81 minutes, with a mean interview length of 63 minutes and a total of 758 minutes of interview data collected.

Once the recording was finished, participants were asked about their experience of being interviewed. None of the participants had appeared particularly distressed during the interview however options for further support were described again. Participants were reminded of their right to withdraw their data for up to a week after the interview, and it was ensured that participants knew how they could contact me to request their data be withdrawn. Participants were given the opportunity to ask any questions, and were then thanked for their participation. Immediately after the interview I saved the audio recording in a secure, password protected online cloud storage, ready to be transcribed at the earliest possible opportunity.

Analysis

The data was analysed using Braun and Clark's (2022) Reflexive Thematic Analysis. Reflexive Thematic Analysis has six main phases, although these are considered to be iterative rather than sequential. The phases are as follows:

1) Phase One: Familiarising yourself with the data set.
   I endeavoured to immerse myself in the data set in order to become deeply familiar with its content. I decided to transcribe the data myself as part of the familiarisation process. Once the interviews were transcribed, I read through the transcripts multiple times, noting down some initial thoughts.
2) Phase Two: Coding.
   In Reflexive Thematic Analysis, coding describes the process of assigning descriptions of meaning to particular extracts of data. I worked through each

interview systematically, coding all data that appeared to be relevant to my research aim. I used a mixture of semantic codes, which capture explicit meaning, and latent codes, to allow for exploration of more implicit meaning. I initially recorded my codes through the comments feature on the Microsoft Word documents of the transcripts; an excerpt from a coded transcript can be found in Appendix F. In order to ensure I was being thorough in my coding, I went through each interview transcript twice. As I worked through the interviews, I found myself returning to some of my earlier codes and refining them as I developed my ideas about the data. Ultimately, I ended up with 638 separate codes. When I had finished coding I collated the segments of data I had assigned each code, using Microsoft Excel to organise this.

3) Phase Three: Generating initial themes.

   Once I was satisfied with the coding, I printed and cut out the code labels in order to begin generating the initial themes. Printing out the codes allowed me to physically move them around and experiment with putting codes together that appeared to have some shared idea behind them. As I began to develop candidate themes, I returned to the Microsoft Excel spreadsheets with the coded extracts of data, and collated all the data that related to each of these candidate themes (for an example see Appendix G). As I began to generate candidate themes, I started writing about what it was that led me to collate the particular codes under this theme. I continued to do this as I further refined these themes.

4) Phase Four: Developing and reviewing themes.

   In this phase, I read through the data extracts I had collated under each candidate theme to assess the extent to which they fit together. I also returned to the dataset as a whole, reading through the interviews and reflecting on whether the themes I had generated captured a pattern of shared meaning. Some of the initial candidate themes I had considered were merged with others at this point, as their meaning did not appear to be distinctive enough. Others were split into subthemes in order to develop more nuance.

5) Phase Five: Refining, defining and naming themes.

   Overlapping with phase four, in this phase I further considered whether the themes I had developed were clearly demarcated with a clear central organising concept. When I was satisfied that they did I often used this central organising concept as I decided on a name for my themes. I also further reflected on how the themes related to one another to tell a story about my data.

6) Phase 6: Writing up.

   As described above, I had already began writing about my themes when they were under consideration, as part of my process of deciding whether my candidate themes conveyed something meaningful about the data. At this phase, I further developed my analytic narrative under each theme, and selected quotes to accompany my narrative. In selecting my quotes I attempted to identify vivid and compelling extracts, while ensuring I was including a selection of quotes from across the interviews, as the focus was on identifying shared meaning across the dataset.

These phases took place over a protracted period of time, in order to ensure sufficient depth of analysis (Connelly & Peltzer, 2016). In line with the reflexive approach, I considered my own experiences and perspectives of the topic at hand as outlined in my statement of positionality throughout the analysis.

Ethical Considerations

A formal application for ethical approval was made to the University of Essex ethics committee on 20th December 2022. The project received approval on 26th January 2023 (see Appendix H). No one was approached to participate in the research until ethical approval was granted. An application for an amendment was submitted on 7th August 2023 and approved on 17th August 2023 (see Appendix I), allowing for a greater range of recruitment avenues to be pursued as described above.

In designing the research, care was taken to attend to ethical issues in order to mitigate the risk of harm occurring. Steps were taken to ensure that participants were giving informed consent to participate in the research. Participants were sent an information sheet with details about the research in advance of the interview and its main points were summarised again by myself prior to the interview formally starting. Participants were invited to ask questions about the research both before and after the interview. Prior to the interview, participants were informed of their right to terminate the interview at any point without explanation or penalty. No participant opted to do this, but if they had any recordings would have been deleted immediately. Participants were also informed that they could ask to have their participation withdrawn and data deleted up to seven days after the interview, in order to allow time for reflection post-interview. Participants were informed that they could not withdraw their data past this point. Before the interview participants were asked to sign a consent form evidencing that they had read the information sheet, had opportunity to discuss the study and were in agreement with taking part. No financial or other material incentive was offered in exchange for participation in the study.

Steps were taken to ensure the confidentiality of participants. Participant consent forms, which had the names of participants, were stored in a secure electronic file separately from the interview transcripts and collected demographic data. The consent forms of the participants who chose to take part in face-to-face interviews were scanned and shredded as soon as was practicable after the interviews. The audio recordings of the interviews were only accessed by me. As I transcribed the interviews I changed or removed any identifying details, such as where participants had used their own name or the name of a colleague or service. Once the interviews had been transcribed, the audio files were deleted. The full transcripts were only accessible by myself and my supervisors. The data and consent records will be retained and stored in secure electronic files for ten years. Participants were informed of the circumstances in which I could no longer maintain confidentiality, namely, if they disclosed that they or another person was currently at risk. If this had happened I would have discussed this with the participant before taking steps such as contacting their local adult safeguarding board. Participants were anonymised in the write up of the thesis. Participants were assigned pseudonyms in order to bring them to life while maintaining anonymity. It was considered important to report on demographic data in order to give context to the analysis, but care was taken to not give too many specifics. For instance, location was described in terms of broad geographical regions rather than specific places, and the demographics were reported on the sample as a whole rather than for individual participants.

The potential for harm to occur to the participants was considered. Although the research was not directly concerned with personal experiences of trauma, I considered the possibility that participants may become distressed. I considered this may have been a possibility because people might find discussing the difficult life experiences and the impact that they had on the people they cared for distressing. I also considered the possibility that discussing trauma in general might evoke feelings or memories around personal difficult life experiences. I took care to track the distress of participants during the interviews and though I did not observe anybody to become particularly distressed, I ensured that I took the time to ask people about this at the end of the interview. Had someone become distressed during the interview I would have asked them if they wanted to have a break or stop the interview. As part of the debrief, I also reminded participants of avenues they could seek further support from, which were listed on the information sheet.

I also considered the risk of harm to myself as through collecting and analysing the data I would be exposed to accounts of traumatic experiences as well as potentially participant distress. When planning the research I took time to think about whether I was in a place where I could manage the emotional demands of a research project that was focused on trauma. I ensured that I scheduled some non-participant facing time after each interview so I had space to reflect and attend to my own wellbeing, including by seeking support from my supervisors if necessary. When transcribing and analysing the data I ensured that I took regular breaks.

Consideration of quality in the research process

In designing and carrying out the study, consideration was given to how the research could be ensured to be of good quality. There is debate as to how quality can be best assessed within qualitative research (Yadav, 2022). One commonly used set of quality criteria is those outlined by Yardley (2000), which were influential in the design of the present study and are outlined below:

1. Sensitivity to context. It is beneficial for qualitative research to be conducted with an appreciation of the surrounding context, including the relevant theoretical and empirical literature and the relationships between the participants, researcher and wider sociocultural landscape. These were considered in depth in the present study, as described in Chapters One and Two.
2. Commitment and rigour. The researcher should aim to have prolonged and thorough engagement with the research by immersing themselves in the data over a sustained period of time, in order to achieve depth of analysis. The approach to data collection and analysis as described above was planned to ensure as thorough engagement with the research as possible in order to promote commitment and rigour.
3. Transparency and coherence. In order for the findings of the research to be persuasive, the researcher needs to be open about their method and how they have arrived upon their findings, and ensure there is fit between the research's aims, method and findings. This was ensured by the detailed reporting of the method throughout this chapter.
4. Impact and importance. The research should make some contribution to furthering understanding, be that theoretical or practical. The research was designed with this in mind, and this will be discussed extensively in Chapter Four.

These criteria are returned to and given more extensive consideration in Chapter Four, in the section focused on critique of the methodology and study design.

Chapter Three: Findings

Chapter Summary

This chapter presents the findings of the research. The five themes and nine sub-themes generated using Reflexive Thematic Analysis (Braun & Clark, 2022) are summarised and then discussed in turn. Verbatim quotes from the interviews are used throughout to illustrate the analysis.

Findings of the Reflexive Thematic Analysis

From the reflexive thematic analysis of the interview, five themes were generated along with nine subthemes. The themes and subthemes are displayed in the table below.

Table 5

Study themes and subthemes

Theme	Subtheme
Grappling with the meaning of trauma	*Understanding the way people are: connecting past and present* *Empathy facilitates authentic understanding*
Negotiating relationships as a means to helping	*The endeavour to be relational* *The caring relationship isn't a blank slate* *The power in and the power over*
Encountering and being immersed in distress	*The emotional weight of the work* *Needing to cut off to cope*
Space to think is essential	
Navigating a dysfunctional and harmful system	*Trying to work within constraints* *Under the shadow of the institution*

These themes were arrived upon because they appeared to each have a central organising concept that was sufficiently distinct from the other themes, and taken together they told a story about the data that addressed the research aim of understanding how residential care/support workers respond to people with a learning disability who have been impacted by trauma. Efforts were made to avoid producing themes that were simply summaries of everything participants said on a particular topic or in response to a particular question. Where subthemes were used this was to add nuance and help highlight particularly salient aspects of themes. The majority of the themes captured patterns of meaning that were present across all of the interviews in the dataset, although saliency was used to determine what should be a theme rather than frequency. For example, the issues discussed under the subtheme of *under the shadow of the institution* were not present in every interview in the dataset, however, this was still deemed significant enough to constitute a subtheme because it captures something important about the context in which the participants are working. Each theme and subtheme is elucidated in detail below.

Theme One: Grappling with the meaning of trauma

The theme of *Grappling with the meaning of trauma* describes the essential but challenging process undertaken by care/support workers in order to understand how the people they were caring for were affected by their life experiences. It is divided into two subthemes. The first, *understanding the way people are: connecting the past to present*, explores the interpretive stance care/support workers adopted in order to make sense of the ways trauma was manifest in the lives of people with a learning disability. The second, *empathy facilitates authentic understanding* describes how if care/support workers could employ an empathic recognition of their shared humanity with people with a learning disability this facilitated them understanding the impact of their life experiences.

Understanding the way people are: connecting the past and present

This subtheme focuses on how care/support workers made connections between people with a learning disability’s current presentations and their personal histories. This was a crucial first step in being able to respond to the needs of people with a learning disability who are impacted by trauma. In making links between past experiences and the way people were presenting, a range of life experiences were raised by the participants as being potentially traumatic, with interpersonal experiences such as abuse or loss being most frequently highlighted. There was some reflection on the subjective nature of traumatic experiences, and how somewhat mundane events might be traumatic for people with a learning disability in particular:

> *the first things that come to mind usually are like it's like abuse, either physical, sexual, financial, or any form of abuse really, a death of a loved one is often classified as traumatic event in someone's life but... and obviously those are all valid but I think there are also areas that are not as often thought about as traumatic, so maybe you know for someone with learning disability not being able to go out could be quite difficult quite traumatic because they enjoy the activity* – Kacper

Some participants described how events that had occurred many years ago were still very live for people. For example, Megan described the hypervigilance of a resident who had previously been harassed and had stones thrown at him by groups of local children:

> *Yeah, he um he used to sit there and he'd go "them damn kids. Them damn kids". There's no kids darling, you're okay. You're safe you know, they're not going to come back, we're not going to let them.* – Megan.

The participants reflected on the myriad of ways that trauma appeared to impact on the people they cared for. They made reference to the emotional distress that could follow trauma, although they generally framed this in terms of observable behaviour. The idiosyncratic nature of how trauma could manifest was highlighted through examples of behaviour participants considered to be trauma responses that appeared to be in opposition with one another, such as appearing very confident versus very anxious and lacking in confidence:

> *He kind of took the role of, you know, being quite outspoken, he was very vocal, you know, quite fairly, you know, he'd present as being quite confident even if you know maybe he wasn't feeling so much so. Um but yeah, I think he he kind of tried to navigate that in a sense that he wanted to compensate for for what had happened in his life and how he felt in his family, and he would, you know, sometimes he would even say to staff that, you know, "I don't even have a learning disability and I'm perfectly fine. And, you know, I used to work. I used to do this", and he wanted to really kind of portray that image of "I'm fine, and I don't. I'm not less than anyone in that sense or I'm not, you know, I'm not different to others. I'm. I'm just like any other person"* – Omar

> *needed like a lot more reassurance from staff for things that he had done independently for you know [...] like even worrying about, his own own ability to make things like a cup of tea, for example, something he used to do 34 times a day because he was quite an excessive tea drinker. And then like worrying that I don't know, he had put things in in the right order, just a complete lack of confidence* – Liam

The lack of formulaic trauma response highlights the degree of interpretation care/support workers needed to use in deciphering how people's presentations related to their past. The former quote also illustrates the need for care/support workers to go beyond taking things at face value, for instance by not assuming that a confident presentation meant that someone was not affected by their experiences.

The ability to make meaning in this way is also important because the difficulties with understanding and communicating integral to the learning disability means people may be less able to say for themselves what they are struggling with. Participants reflected on the lack of shared language for communicating about trauma or emotional distress:

> *It's so difficult to judge how how that's affecting erm the individuals like because when you're non-verbal erm when your your signing might be limited to two or three signs erm… Yeah, yeah how do you express that I miss someone?* – Christopher

This predicament led some participants to reflect on how they could never be entirely certain about the links they had made between someone's life experiences and their presentation:

> *So yeah, we might well it looks like we're putting two and two together and we are coming up with four, but obviously there's no way of confirming that for definite so there's always a small chance that you know, we've come up with five, but yeah, it's it looks very likely that it is the case* – Daniel.

The particular person that Daniel was talking about had been resident in a service during a time period where abuse was known to have happened, but their records for that period of time were missing. This also raises issues around whether somebody's history is documented or not, particularly for those people with a learning disability who are unable to provide a narrative of their life experiences.

Rather than being a fixed event, making links between past and present was an ongoing process, with some participants describing reappraising the meaning of behaviour as their awareness of the impact of trauma developed. For example, David described working with a woman who appeared to be re-enacting something of a previous traumatic experience, but only being able to conceptualise her behaviour in this way years later:

> *So there's a lady I worked with who umm… was very possessive over a toy doll [...] she was raped as a like a teenager got pregnant and got put into uh, an asylum, basically. And I believe that, I say, this whole attachment to the doll was part of a response to the fact that, say, she did have this child and it was taken away from her and yeah… […] That is something that came to me later on after like reflecting [...] But at the time, especially with no training and I say that home I was probably 18, 19 and at the time working there that wouldn't have thought at all that that would have been linked to about like a history event or because yeah, also my understanding of people with learning disabilities and complex needs just isn't what it is now, right? Like wouldn't have thought anything of it like it was just a behaviour oh she likes that that's it* – David

This quote also emphasises the importance of care/support workers being able to make connections between people's past and the way they are presenting. Without understanding the significance of the woman's attachment to her doll, it seems likely that the grief and sorrow she may have felt for the loss of her baby was also not recognised and therefore not adequately attended to.

Empathy facilitates authentic understanding

The subtheme of *empathy facilitates authentic understanding* describes how the ability to empathise with people with a learning disability was crucial in enabling care/support workers to join the dots between people's life experiences and the way they presented. The consequences of care/support workers being unable to access this empathy are also explored.

Speaking about colleagues who did not appear to be able to link residents' life experiences with how they presented, Teresa reflected on how this may have been a result of a lack of knowledge about trauma but perhaps more crucially a lack of empathy:

> *Um yeah I just don't think they did recognize it […] And so I don't think they had the knowledge to put the pieces together. Um and maybe the empathy that they should have had to understand yeah, so this is why this is like this and this goes with this and this goes with that, yeah, that would be my perception on that* – Teresa.

Further illustrative of this, David, who described above moving from a position of perceiving a resident's attachment to her doll as an arbitrary quirk to something that was likely related to her life experiences, identified that he became able to do this through becoming more in touch with how his own life experiences had affected him:

> *I mean, personally for me it came from more understanding myself more and understanding like stuff I've gone through my for myself and seen how it's affected my behaviour and life and it makes it a lot easier than to look at someone else and go ohh well maybe* – David

Some participants described how having gone through the same life experience as the resident allowed them to understand the significance they may have had. Describing how frequently a resident would become distressed around the death of his parents, Aisha reflected:

> *Erm but you know that's completely understandable because obviously, you know, if I'm honest, I've had a parent pass away and and two years is it's nothing you know it if you it still feels very raw erm and I'm sure that's probably what he's experiencing so* – Aisha

Other participants described a more general stance of appreciating the inherent complexity of the human experience and how that evidently included people with a learning disability. This may have been valuable because care/support workers are unlikely to have had personal experience of all the difficult events that have occurred in the lives of the people they cared for, particularly those that are related being designated as a person with a learning disability, such as institutionalisation.

> *Erm… But yeah look I mean the the big picture though is I think is is is really vital I really do because it well you're humanising people then. Erm… Yeah…. these these fellas you know have a vast landscape in which they erm yeah their lives are complicated and strange erm and fascinating and tragic and you know all those things that all of our lives are erm so yeah you treat you treat them with dignity and respect as you would want to be treated erm that's just a that's a no brainer surely you know?* – Christopher.

In this quote Christopher explicitly names the importance of humanising people with a learning disability. Again, this may be particularly important given how many of their traumatic experiences may have been linked to a positioning of people with a learning disability as less than:

> *we had a guy he was again he'd been abused as a child by his parents erm his best friend was a washing machine would you believe? He wasn't allowed to go*

> *out because his parents were ashamed of him because he had a learning disability* – Megan

Without an empathic understanding that the way that people were presenting was related to difficult life experiences, care/support workers sometimes drew more pejorative conclusions about why people were behaving the way that they were. Several participants described having colleagues who interpreted signs of distress as being wilful bad behaviour:

> *because I think it can be easier to see things more as like this person's being difficult or erm this person, like I said, was attention seeking* - Freya

It follows that the way care/support workers respond and treat people is likely to be different if they understand them as being ‘difficult’ rather than acting a particular way in response to trauma. Illustrating this point, Daniel described his view that without empathy and understanding, care/support workers are more likely to treat people poorly:

> *if you get someone who doesn't understand and isn't empathetic and someone's coming at you with a right hook unfortunately I can imagine some people in that job will throw one back. Unfortunately like we have seen in some of the institutions people do end up doing stuff like that* – Daniel

Theme Two: Negotiating relationships as a means to helping

The theme of *Negotiating relationships as a means to helping* describes the centrality and significance of the relationship between care/support workers and traumatised people with a learning disability. It is comprised of three subthemes. *The endeavour to be relational* refers to the qualities care/support workers attempted to imbue in their relationships with residents in order to help them overcome their trauma. *The caring relationship isn't a blank slate* describes the interaction between the histories and characteristics of care/support workers and residents in their relationship with one another. *The power in and power over* explores how the importance of the relationship afforded power to care/support workers, and how they navigated that.

The endeavour to be relational

The subtheme of *the endeavour to be relational* describes the qualities that care/support workers aimed to bring to their relationships with residents in order to ensure they were positive and therapeutic. The participants perceived their relationship with residents as an opportunity to offer those who had had harmful interpersonal relationships an experience of being related to in a different way that would ultimately help them to overcome their trauma. Daniel described this using the following metaphor:

> *people who have experienced trauma have constantly being given dirty water like horrible it's full of disease and like just minging stuff you know all in there and then but that's the only water they've been given so they just drink it because you need water to survive. And then I suppose our roles as a support worker or anyone that works with trauma is sort of you come along with a nice fresh bottle of Evian you know and they're like and you start slowly giving them sips of that. And yeah I think every every every time you work with someone with trauma, as long as you're going in and working in a positive sort of person centred way that you're slowly showing to that person that there's you don't have to drink that dirty water.*

> *You know there is an alternative out there and you know you are slowly bringing them round* – Daniel.

In this quote Daniel offers a recognition that the process of developing these reparative relationships is one that takes time. Other participants highlighted this as being a lengthy process because of the amount of time it took for people to have trust and feel safe with those caring for them:

> *it might take someone like years to build up trust in you and the fact that you come with good intentions and erm you're not gonna hurt or reject or cause them any harm* – Freya.

There was a sense that it was being consistent and reliable that allowed trust to build, although this might not always happen in a linear fashion, as the therapeutic relationship may become challenged at times. Care/support workers endeavoured to convey that they would be there for people no matter what:

> *I think it's fair to say, yeah… this came more as well especially the more I worked with errr non-verbal people. Umm… I think building up the relationship… Just…. Reinforces a lot of things that you are there to help and erm even even though I say if they do suffer from challenging behaviours and there is things like that doing what's called the therapeutic rapport, building up relationship afterwards as well to understand that like I'm not taking it personally or like I I'm still there to help the person no matter what has happened or what they've done or what. Yeah, it's I think it's very important myself.* – David.

Many of the participants spoke about the people they cared for with a sense of genuine esteem and a commitment to supporting them. Participants described how creating positive experiences for people over time allowed them to begin to feel safe enough to begin engage with the world around them:

> *Or like when we when we take him to the park and we'd go for a wander, he'd suddenly walk off […] And because I hadn't shouted him because he'd left my side he started to say well I'm actually allowed to do this. I'm actually allowed to go and look at something that I want to look at and it got to the point where you'd walk along and he'd be he'd be chattering to you about what you'd done, what he wanted to do tomorrow, how much it was looking forward to what he was gonna to do the next day and you're thinking yeah you're getting there, you're coming out of this* – Megan

In this quote Megan also conveys the importance of care/support workers promoting residents' autonomy and ability to exercise choice over their own lives. This again is an important antidote to experiences of trauma which often involve a violation of a person's autonomy.

The caring relationship isn't a blank slate

The subtheme of *the caring relationship isn't a blank slate* captures how the development of the relationship between care/support workers and residents did not occur in isolation. Rather, many participants identified how the personal histories of both residents and care/support workers influenced the ways in which they related to one another, and this was something that needed to be considered by care/support workers in their efforts to build positive relationships with residents.

Participants spoke about how residents' previous interpersonal experiences could lead to strong emotions being provoked in their interactions with care/support workers that were evocative of previous experiences. Beth spoke about being in the difficult position of having to enforce boundaries around food consumption because of resident’s physical health, and how that was distressing for her given her history of being deprived of food by her parents as a child:

> *And I guess and that can if she takes that as ohh staff aren’t being very kind it would have it could evoke similar feelings to what she's felt previously when she's gone through the more difficult situations when she was a little girl and when she was growing up and the difficult the difficult emotions she has felt. You you can understand how how that would link how can that can affect how she's feeling in that moment then* – Beth.

Participants reflected on how as well as trauma affecting how residents responded emotionally to the actions of care/support workers, they may also have developed particular patterns of relating to care/support workers based on their experiences. For example, Teresa described some residents as attempting to exert control over care/support workers, often over seemingly trivial matters:

> *and that is their control. OK, so if you imagine they've been through trauma, okay, and they need to get control of their life, okay so they will, they will manipulate that unit and that staff team to get what they want* – Teresa

Although the language of manipulation here seems somewhat pejorative, it is qualified with an understanding that this need for control was perhaps about feeling safe and making up for the loss of control associated with a traumatic experience.

As well as affecting how they relate to care/support workers in general, participants described how people’s histories affected how they related to care/support workers with particular characteristics. Gender was often cited as affecting how safe it felt for residents to form relationships with particular care/support workers:

> *unfortunately he really struggled to be integrated with others and had serious trust issues with males. He was sexually abused by his dad growing up. So it was a very difficult erm experience for him and he really struggled to be around males*. – Keeley

Care/support workers may also sometimes be evocative of particular figures in people's lives in a way that facilitates a positive relationship:

> *he changed completely with this with this with this one support worker. It was one of the night staff and we were trying to work out what it was, what's you know what's what's your trick? What's what's the yeah what's what what what's your magic that that you do? And she looked like his mum.* – Christopher

What both these quotes highlight is that factors beyond care/support workers' control may affect how they are related to by residents. There was also a sense that care/support workers' own histories could contribute to the ways in which they navigated their relationships with residents, and that this was something that needed to be reflected on. Two participants spoke about the influence of being parents in how they related to residents. The experience of being a caregiver in this way imbued a sense of being more equip to deal with some of the challenges of providing care at work, but also affected how they responded to residents on an instinctive emotional level. Megan spoke about having to inhibit a maternal impulse to offer physical comfort to a resident in distress:

> *Yeah, you've got and fighting it, especially as a mum, fighting that impulse to go and do that sometimes it'll break your heart. You've got someone screaming the place down and all you want to do is go and give them a cuddle and say you're okay, nothing is going to hurt you but you know if you do that you're going to make it worse.* – Megan

There was a sense that if care/support workers did not sufficiently reflect on their own contribution to the relationship then their ability to meet the needs of residents would be diminished. Christopher described believing that the onus was on care/support workers to mitigate the impact of their personal histories on how they interacted with residents, who may be less able to do this:

> *You know it’s it's a really, it's a complicated job and it's it's a job that requires… erm… it requires the support worker I think to be really on the ball and really try to take themselves take them taking themselves out of the picture which you know quite often people come to work with a lot of baggage with them you know it's it's not about that. You you have to you leave all that crap at the door and yeah we're doing our job here* – Christopher

The power in and power over

The subtheme of *the power in and the power over* describes how the importance of relationships placed care/support workers in a powerful position, particularly given the unequal nature of the relationships and the relational context around people with a learning disability.

While some participants gave examples of how much residents benefitted from continuing bonds with their families, it was however very common for participants to describe residents who had few or no relationships beyond those that they had with care/support workers and other professionals:

> *Another one of the sort of top traumas that people in residential places with learning disabilities do experience is erm the loss of their family. Which happens a lot you know erm… people kind of drift into the drift into into the system erm and you know they might they they might not have any contact with any extended*

> *members of their family at all. I certainly know a couple of individuals who who don't have a family at all erm or at least not a family here has any kind of contact with them* – Christopher

Here Christopher conceptualises the absence of family as being a trauma in itself. There was a sense throughout the sample that where people with a learning disability were not in contact with their family, this was generally not a decision that they had made for themselves, and being in residential care afforded few opportunities to forge new relationships. Care/support workers reflected on the sense of pressure and responsibility in being the only relational figure in someone's life, while not being able to fulfil the same need a friend or relative might:

> *and that can be quite erm… difficult for staff because it means that like it's sort of all on them and that can be quite difficult when like they come to you as another professional and are more sort of like seeking out care or friendship or something like that when that's not really the position that we're in to offer.* – Freya

Aisha further articulated a dilemma faced by care/support workers around how the professional nature of the relationship between themselves and residents influenced where boundaries were drawn around matters such as physical touch. While residents might naturally want physical comfort in times of distress, and care/support workers may feel drawn to offer it, this may contravene service policies:

> *you're not allowed to hug somebody, you're not allowed to you know, hold their hand [...] but you know sometimes it's human instinct to kind of desire that or want*

> *that when you're when you need comfort in times of, you know, difficult life situations* – Aisha

Reflecting further on the unequal nature of relationships between care/support workers and residents, Liam spoke about how their presence in residents' lives was contingent on the parameters of their employment, and so for residents the opportunity to be around someone may end as their shift ends:

> *that person's shift ends and they go home to I don't know, friends, family to do social things but that service user you're supporting apart from the night's staff, for example, or someone who's there, that might be the end of the interaction for the full day. Umm, there isn't a family or friends to just call or to talk to or… sometimes it's nice to have staff there, but sometimes I think it's nice to have someone who isn't paid to to be around you.* – Liam

Ultimately, care/support workers could choose to leave their jobs, meaning that the relationship ended but never on the residents' terms, perhaps similarly to how their relationships with family might have ended. Daniel likened the experience of staff leaving to going through a break-up, and wondered how this experience might be internalised by people with a learning disability as a rejection:

> *It's like going through a break up every every year possibly or even sooner depending on how many people come in and out […] whenever I've left somewhere it's really hard to say because you know, the natural question again if if you're in a relationship and you break up the first question you ask, like, what have I done? Why are you leaving? So you know those people have learning disability are thinking why? Why are you leaving me? Why why why is that? And*

> *yeah unless you've got a good reason or you can explain it well, it's you know it's going to be hard for them to understand*. – Daniel

In this quote Daniel also alludes to the issue of frequent staff turnover and how this might mean people with a learning disability are continuously having to cope with their relationships ending, diminishing their ability to build trust in care/support workers. While the professional nature of the relationship between residents and care/support workers could be considered to reduce the intimacy of the relationship, conditions in care may mean that the level of contact between care/support workers and residents is intense and unusual:

> *cos it can be a very full on job like you are literally you know in, in my personal life do I spend 24 hours a day with someone? Absolutely not! Would I spend more than a couple of hours at a time with someone, probably not you know and you're on you're on eight nine hours sometimes consistently next to someone and working with someone* – Daniel

This perhaps amplifies the significance of the relationship for residents with a learning disability, as well as the power afforded to staff as people are highly dependent on them for both for practical care and for relational warmth.

Not all staff appeared to appreciate the importance of the relationship for people with a learning disability. For example, David spoke about having some colleagues who would prioritise completing procedural tasks and paperwork over developing relationships with people, and would therefore keep their distance:

> *some of them didn't see that as part of err like the job it was not part of it. It was they, they were there to, uhh, like I say do the support they needed, but it wasn't*

> *kind of like we'll be friends or get to know each other. What they knew they had the paperwork. That's all they needed.* – David.

This focus on procedural, practical care rather than developing relationships is at odds with the unanimous belief in the power of relationships in supporting people with a learning disability to overcome trauma put forward by the participants. How residents may experience this withholding of relational care and warmth by care/support workers was further elucidated by Omar:

> *but from what he said it was kind of just, not feeling really listened to by staff, maybe, and sometimes just feeling like… obviously it was he was in a supported living home and it was kind of, you know, that was his place. That was his place of living and sometimes he felt like in his own house he felt unwelcome unfortunately* – Omar

What is particularly poignant about this example is that this treatment appeared to repeat how this particular man had been treated in his own family, in that he had been overlooked and excluded on account of having a learning disability, thus potentially re-traumatising him.

Theme Three: Encountering and being immersed in distress

The theme of *encountering and being immersed in distress* explores the potentially overwhelming emotional intensity of working with people with a learning disability who are impacted by trauma. It is split into two subthemes. The first, *the emotional weight of the work* explores the often painful emotions evoked in care/support workers through their role. *Needing to cut off to cope* details the felt necessity of detaching from these feelings in order to perform the demands of the job.

The emotional weight of the work

The subtheme of *the emotional weight of the work* captures the various aspects of the role that care/support workers found to be distressing. Care/support workers reflected on the impact of exposure to histories of abuse, particularly through hearing about difficult life experiences from residents directly. This was especially difficult when there was a sense that the trauma appeared to be unprocessed for the individual and they were repeatedly raising it with staff in an attempt to cope. For instance, Freya conveyed a feeling of becoming consumed by the traumatic narratives she was continuously exposed to:

> *I think just everything really erm just you feel sort of almost like you're living the trauma of that person, especially when they bring it so frequently erm and I think that, yeah, hearing stories can be quite difficult when it's happening quite frequently and when you aren't really getting that many breaks from it erm…* - Freya.

The way people spoke about their traumatic experiences was sometimes, but not always, accompanied by significant distress. Conversely, as described above, distress was not always accompanied by verbal articulation of a traumatic experience. The distress people could exhibit was often extreme and several participants described how ill prepared they felt to have to support people through this:

> *And and I guess like, it's always like you you read about things, don't you like you read about ohh, this person might display this behaviour, but it's not until you see it you see it first-hand that you kinda you kinda feel that shock and like ohh even*

> *though I've read it, doesn't… You know what I mean, it doesn't sort of hit home until you see it* – Beth

The behaviour referenced here by Beth included violence towards staff and self-harm, which many of the participants described being exposed to as part of their work with traumatised people with a learning disability. As well as resulting in emotional distress, several participants described sustaining serious injuries from residents such as broken bones. Megan for example, described an incident where she had not been warned that a particular resident would be distressed by the presence of a female member of staff, resulting in him physically assaulting her:

> *and I ended up at the bottom of seven steps with a dislocated knee, a dislocated ankle and two broken toes* – Megan.

Care/support workers also had to cope with the enormous responsibility of preventing people from harming themselves in potentially grave and permanent ways:

> *That led to him quite severely harming himself, he almost scratch off his eyeball...* – Kacper.

The particular event that led to this resident becoming so distressed that he self-harmed in this manner was the advent of the restrictions associated with the Covid-19 pandemic, which were sudden and inexplicable to him. Of course, the Covid-19 pandemic was largely unprecedented for everyone and so this also raises the point that life experiences that are distressing for residents may also affect care/support workers:

> *because everything changed drastically and some of the people were just unable to comprehend what is going on. Not only people with learning disabilities and autism, but also us really.* – Kacper.

When people were going through distressing or traumatic circumstances in the present, care/support workers were sometimes placed in the position of having to break difficult news to people and thus feeling as though they were inflicting distress on people. This provoked various emotional responses in care/support workers, such as guilt, anxiety and anger. For instance, Megan spoke about having to tell a resident that his mother no longer wanted to have a relationship with him:

> *we had to tell him that mummy couldn't do it [...] He screamed for three hours. He hit himself around the head. We he has like a rugby helmet, we had we gave him his hat he put that on, he'd beat himself up. He screamed, he bit himself, he threw things. He kept looking at me going "mummy mummy mummy". "No darling. No mummy". And he was like "you ain't mine" and my heart's breaking. It was horrific.* – Megan.

Some participants expressed a sense of guilt or remorse around the shortcomings they perceived in the care they had provided. For example, David described how as he became more aware of trauma he became more emotionally affected by the work, and part of this emotionality was about wishing he could have provided better care for people that accounted for this:

> *Umm I say so yeah, getting older is when I look back at it now and it's a bit more it affects me more and seeing how much it must have affected that person and um, yeah, how things could have been done differently* – David.

Needing to cut off to cope

The subtheme of *needing to cut off to cope* describes how care/support workers endeavoured to modulate their emotional responses in order to carry out their role. Some participants spoke about how the demands of the job were such that they were left with no space to feel. For example, describing his response to a resident self-harming by scratching at his eyes, Kacper stated:

> *No, I I mean it sounds bad I know but no I didn't really... I didn't really care. Meaning before I even... When it first happened I didn't have time to to care, the first response was to stop it* – Kacper.

Here Kacper conveys that becoming emotional would have gotten in the way of managing the demands of the situation at hand with potentially severe consequences. Given how quickly this situation arose it seems that not becoming emotional was likely not a conscious decision that Kacper made, but rather an automatic response which did help him to respond effectively. Other participants described making a more intentional effort to suppress their feelings. For example, David reflected on the potential for staff emotionality to be contagious to residents, potentially having a negative impact on them:

> *I try not to let it affect me because… umm… Especially with the people I work with at the moment, it's everything's kind of err like a reflective chamber, if I'm letting this take it like showing effects of things like that as well as err the people pick up*

> *on it as well, and it kind of just reverberates, I think, so I always try and just keep myself… clear* – David

There were differences within the sample as to the extent to which having to cutting off from feelings was seen as desirable. Some participants, particularly the men, referred to certain traits and abilities they felt they had around not becoming emotional as being strengths:

> *Erm yeah I don't I don't I don't let things like that bother me. Some people get bothered by things like you know repetitive by repetitive behaviours and noise and things like that. I've got like a magic button in the back of my head that I just switch off yeah that's yeah a slight erm mental stepping back from things just to go, okay right we're doing this are we?* – Christopher

Other participants seemed to view cutting off from their feelings as more difficult but necessary as the lack of support available to them in their role left them with few other options to cope with any distress evoked:

> *Um I think obviously the physical behaviour and things that was tricky, because obviously you wanted to feel safe working around him […] and it was quite upsetting reading his care plan and kind of what he had kind of experienced. Yeah, that was quite, quite tricky to kind of process, and I found that in kind of other people I've worked with as well, especially when you don't get um so much like support debrief from your managers. And you're there reading, reading through quite a difficult care plan that yeah it's kind of you end up turning your kind of work brain on and kind of just getting on with it and detaching from what you're reading in a little way, yeah.* – Keeley.

As well as the implicit messages around the acceptability of becoming distressed conveyed by the lack of support available for care/support workers, some participants described being explicitly told that being emotionally affected by their work was unprofessional:

> *certain places you'll you'll go and you'll say you know "I can't cope with this". "Well you're the wrong career"* – Megan

Rather than reducing distress, Megan described how this message may lead to people taking their distress home with them and ultimately burning out. The implication here is that cutting off to cope is unlikely to be a sustainable strategy for care/support workers.

Theme Four: Space to think is essential

The theme of *space to think is essential* describes the importance of care/support workers having space to think about their work, given the above-described complexities. While being supported to think and talk about the work was certainly not a given in residential services, participants saw it as a vital condition for providing good care. The ways that care/support workers attempted to negotiate a lack of formal opportunities to be thoughtful about their work are also described here.

Amongst the participants there were several who described feeling well supported to do their jobs. The essential quality of this support, be it through training, discussion and reflective practice groups or individual supervision, was that it provided care/support workers with the time and space to think and talk about the work they were doing. For example, Freya described how this facilitated her having an empathic understanding and avoiding getting pulled into unhelpful ways of relating to residents:

> *I think what reflective practice and what supervision erm allows is a space to look at behaviours and ways of relating and erm things that people say in a way that offers more empathy or understanding or erm just to offer something more helpful for the person and that, I guess more helpful for the staff as well cos you're not getting yourself caught up in loops that this person's trying to erm be attention seeking or trying to cause us stress or alarm erm and it's more just that this person is erm relating and in the only ways that they know how or that might just be how they see things and I guess it's just important to have that space to sort of unpick things and to think about things from a different perspective*. – Freya

Liam further reflected on the value of care/support workers coming together to think and reach a shared understanding of the needs of the people they were supporting, to avoid inconsistency of approach and trauma related interpersonal dynamics being recreated by the staff team. He spoke about a case workshop facilitated by a clinical psychologist he had recently attended with regards to a particular woman who the staff team had been struggling to support:

> *the push and pulls were like so extreme, she almost wasn't functioning if there were some members of staff in and there was other members of staff she suddenly was like a domestic goddess I suppose. So yeah, it was just a case workshop to understand why she might display these behaviours and then I guess some problem solving afterwards […] the key message probably with this service*

> *user was just ensuring that everyone supported her the same like the consistency was really important* - Liam

As well as facilitating better care for residents, having space to think was also protective for care/support workers’ wellbeing. Again, this is important given the above-described emotional intensity of working with traumatised people with a learning disability. Beth described how beneficial it was for the staff team supporting a particular woman to get together and reflect on how working with her made them feel:

> *staff who have worked with her for a long time and might be experiencing burnout erm cos experiencing burnout you kind of forget about making those links back. We need to remember the reasons* – Beth

This quote further illustrates the importance of care/support workers being supported with the emotional demands of their roles, as Beth identifies here that care/support workers’ capacity to empathise with people may diminish as they become more affected by burnout, perhaps leading them to lose their ability to have a compassionate understanding of the people that they care for.

The larger proportion of participants who described feeling unsupported in their roles also articulated that they would perceive some value in having space to think about their work when asked about how support for care/support workers could be improved on. For example, David responded:

> *some of it, I think would just be a space to actually… Umm... be able to like take it in yourself and be able to, like, deal with some of it yourself and how you can either take it on or like there’s… there’s very little staff support in the years I've worked over, I mean… Yeah…. So with deaths and I say the cases I've had,*

> *where I have worked with the people that were unfortunately abused. There's no real support for the staff involved* – David

Here David touches on the previously discussed issue of care/support workers having to support residents with circumstances that they too are distressed by. Without space to think about how immensely challenging this is, the emotional cost of this for care/support workers is likely to be great.

In the absence of formal spaces to discuss and process the impact of the work, many care/support workers relied upon and valued the support of peers in the service:

> *So you know you make friends in the service anyway. And sometimes you'd go look, "where's your where's your user? Where's your person?" "Oh they're in bed" say. "You want to go for a fag?" It's like, yeah come on. There wasn't a day that went past where somebody didn't walk into another person's house walk up to staff member and just grab them and give them a cuddle because they'd had a bad day. You know, then it was "look, mine's okay. Mine can be left for 5 minutes. Let's just stand outside tell me everything. Tell me what's happened". And while they were doing an activity you'd be like offloading to your mate* – Megan

Of course, being able to seek out peer support was contingent on there being a culture within the staff team of emotional responses to the work being discussed openly, which was not always the case. A further difficulty with reliance on peer support was that sometimes care/support workers were supporting others when they themselves had been exposed to the same stressful and intense circumstances. For example, Teresa spoke about the efforts she went to as the most senior care/support worker on shift to support her colleagues, while not getting any support herself:

> *having senior responsibilities is immensely challenging because you have to manage not just the welfare of the staff but the welfare of the clients as well […] So it's it's a massive responsibility umm and when you're not… appreciated for that responsibility level, it can be um harder. And you have to sometimes debrief when you finish a difficult shift and get the staff team together and say like, "okay, what's gone on here? How are you feeling?" Which is what I used to do when I seniored and we had a difficult shift.* – Teresa

Theme Five: Navigating a dysfunctional and harmful system

The theme of *Navigating a dysfunctional and harmful system* considers the wider context of support work and the care system, and how this impacted on residents and staff. It is split into two subthemes. The first, *working within constraints*, details how conditions in care often hampered care/support workers' efforts to help traumatised people with a learning disability. The second, *under the shadow of the institution*, captures participants's reflections on the legacy of institutionalisation, and how this source of traumatisation may not be in the past just yet.

Trying to work within constraints

The subtheme of *trying to work within constraints* captures a sense that while care/support workers were trying their best, there many aspects of the social care system that restricted the efficacy of their efforts to support traumatised people with a learning disability.

Participants reflected the skill required to provide good care, and how this was not generally appreciated within society, with care/support work often being perceived as an unskilled job:

> *in some respects support work is it's in my experience is looked down upon but actually it's an incredibly complicated job and you're you're dealing with you know… the individuals we support you know are incredibly complicated* – Christopher

Poor working conditions such as low pay and lack of investment in staff development were seen as being reflective of the lack of value placed on care/support workers. Many staff described how the training they were given did not recognise and equip them for the complexity of their roles. Trauma was rarely a specific focus on training, and generally practical matters were the focus:

> *Um… The reason why I'm I'm pausing on that is because I think I've had really good training, but it's been more around… policies and processes and procedures so you know, kind of the formal bits and bobs and legislations and things like that* – Aisha

There was some reflection on PBS, which many participants had received training in as it was the dominant philosophy of care in their services. PBS was generally seen as having some value in guiding how to respond to what was termed challenging behaviour, but with limitations in addressing trauma:

> *I guess PBS is very more behaviour management, isn't it so whilst... it I suppose it some of the theory probably does overlap with the trauma stuff like and just how to treat people and showing them you know that, you know, make sure you're working with them for them etcetera. But yeah, that it's never going to tackle the the real issues* – Daniel.

This led to further reflections around the role of care/support workers. Participants distinguished themselves from professionals such as psychologists who would be able to directly treat the impact of trauma through the provision of therapy, and emphasised the need for this additional care and expertise to be available to people. Several participants spoke about trying to advocate for the people they cared for to get further professional support, and how this often didn’t materialise:

> *she would she would melt down but she wouldn't express anything, and then she'd suddenly become verbally or physically violent. And we, we’d say to our managers, like, look, we don't know how to support her we are really struggling with this, but nothing, they wouldn't, it was just like talking to a brick wall I'll be honest. We she needs specialist erm kind of mental health support like with regards to trauma, and therapies put in place for her. She we could quite clearly see that she needed some sort of therapies to help her but that would be yeah, that was really tricky actually.* – Keeley

Keeley conveys a sense here of being out of her depth trying to care for this resident in the absence of any specialist trauma support, and without having had any training on trauma herself. This is clearly an immensely challenging position to be in, and one that risks negative consequences for both staff and residents alike.

Care/support workers spoke about the pressures of their job with there being a sense that in many care homes the level of staffing was determined based on people’s practical needs rather than emotional ones. Additionally, issues around short staffing were such that some participants described situations where they were struggling to provide even the most basic practical support, let alone meet people’s emotional needs. For instance, Aisha described how:

> *it can feel like there's a lot of pressure erm quite often you'll handling emergency situations simultaneously and it's it's difficult to prioritise what you can work on*

> *and who to kind of dedicate time to and when and you're kind of multitasking and juggling multiple things for quite a long period of time and it's physically demanding as well and then from a residents point of view, of course, you know they're not getting the support that they need, they're having to wait for medication or the having to wait to go to the bathroom, which is not neither of those situations are ideal and some of those residents aren't able to, especially when it comes to the bathroom, they're not able to wait* – Aisha

Of course, the potential psychological impact of living in a service where those upon whom you are reliant to meet your basic needs are not sufficiently available should not be underestimated. The recruitment crisis in social care led to many services being unable to be selective about the people they were hiring. For example, Omar described how he had colleagues who showed little care or regard towards the people they were supposed to be looking after, but that nothing was done to address this as there was felt to be no alternative:

> *I think that was quite um I think really bad thing to happen, but again it was, you know, the majority of them could have been agency staff, some of them were even permanent staff and there wasn't really much that the manager could do or did do in that sense because we were so low on staff. Um, and they kind of, yeah, just accepted it for what it was* – Omar

Participants reflected on how the nature of the settings they worked in meant that people were often living alongside people they would not have chosen to live with, who may have very different and conflicting needs. For example, Keeley spoke about a resident moving into their service who was more intellectually and physically capable than the other residents, with a high level of need around his mental health:

> *His past traumas did kind of bring on a lot of behaviours which were sometimes physical, which is quite difficult, because […] he had, as I said, schizophrenia borderline personality disorder and autism. And the other residents in the residential unit had profound learning difficulties. A lot of them were nonverbal and in wheelchairs so to have those completely different type of client that were physical like quite violent behaviour at times it was quite yeah it was keeping the residents safe* – Keeley

As well as having to assure the physical safety of the other residents, this also raises the question of what the psychological impact of this behaviour may have been on the other residents and how safe they may have felt in what was meant to be their home – something that is crucial for anyone but particularly for trauma survivors.

Under the shadow of the institution

The subtheme of *under the shadow of the institution* explores how far from being consigned to history, the legacy of institutionalisation was still alive in many people with a learning disability and services. Several participants, particularly those who were slightly older and more experienced, described working with people who had been in long stay hospitals in the 20th century and the impact that the abuse in these institutions had on them. For instance, Christopher spoke about how a resident who had been mistreated in a long stay hospital several decades previously still responded to staff as if they would treat him in this way:

> *a lot of these guys were in very bad institutions in the um late 70s and 80s. You know wandering around for for 12 hours a day, that sort of thing. Being hosed down in some place I think. [..] There was one guy that was in one of the other houses of the charity that I work for erm if two support staff approached him he*

> *would get down on the floor immediately. He would just he would lie down and jump [...] he'd been very badly treated erm and was regularly put on the floor by people who were supposed to be helping him erm so his reaction when when approached by two support workers was like lie straight down you know "yeah I'm on the deck gov" sort of thing* – Christopher

While care/support workers were positive about the advent of deinstitutionalisation, they reflected on how the transition into residential care and fewer restrictions could feel distressing and overwhelming for those who had lived the majority of their lives in hospitals:

> *they are possibly never going to unfortunately fully come out of that because they have lived in institutions their whole lives in these hospital settings so whilst their lives are better sometimes that in itself can upset people because they don't know how to deal with it they don't know yeah, it's yeah they're so conditioned to living in such a way and in horrible situations that, you know having all these nice things is is hard for them. Yeah. "Oh God I can choose to do this. I can choose to do that. I don't know what to do", you know and completely lose it* – Daniel

What both these quotes illustrate is the need for care/support workers to understand the potentially enduring impact of institutionalisation. This was further articulated by Megan, who described having younger and more inexperienced colleagues who did not appear to comprehend the impact of institutionalisation, and were therefore not able to hold it in mind when considering how they cared for people:

> *you've got like an 18 year old who's just coming off the street who's never cared for anybody being given somebody who's lived their life in a institution where they've had to put their hand up to go to the toilet because they don't, they've*

> *never seen it, they've never heard of it, they haven't got that experience of of this being that sort of… culture for want of a better word, they don't know how to deal with it. Erm and I hate to say it a lot of young people think it's funny. They think it's amusing, you know oh he's put his hand up to ask to go to the toilet. Yeah, that's all he knows, you know* – Megan

Megan further reflected on how it is not just treatment in now closed institutions that still impacts on people with a learning disability. Rather, abusive and neglectful treatment continues to be a problem in learning disability and other health and social care services:

> *there is a culture […] you know, don't give them the choice, take the choice away. There's still that culture and I think that needs highlighting, that that is still even though it's completely illegal it's still going on people's choices are still being taken away from them and I think it's something it needs highlighting that this isn't this isn't something that happened 50 years ago this this is happening now* – Megan

Megan described being so concerned by one service she worked in that blew the whistle, resulting in CQC taking enforcement action against the service. In a similar vein, Keeley recounted an experience of going to an unfamiliar service as an agency care/support worker and discovering ongoing ill treatment:

> *he wasn't being served an adequate diet at all. […] his room was an absolute, horrific state. It was filthy. It was just litter and rubbish everywhere. It it it was disgusting, like dirty toilet paper strewed all over his room. Erm his sheets I'm sorry this is it was foul, his sheets were like covered in dirty bodily fluids, […] it was quite upsetting because the chap was non-verbal. He wasn't able to communicate, and I also cos I was agency, I didn't really, I didn't know him as*

> *such, and when I was there he spent the whole time in the lounge under a blanket hiding. And I was like, something's not right there. You're spending the whole time you're like hiding under a blanket. And I was there a six-hour shift? So yeah, it was, he was kind of appeared in kind of shut down mode like, quite… And when yeah, certain members of staff came in, he'd hide under the blanket even more…*
>
> \- Keeley

These experiences suggest that there are likely still an unknown number of people with a learning disability being traumatised by the very people who are meant to be looking after them. This again emphasises the great power care/support workers have in their role to both help people and further harm them, and the need for measures to be taken to ensure people with a learning disability's rights are upheld.

Chapter Four: Discussion

Chapter Summary

In this chapter the findings of the present research are summarised. They are then discussed with reference to the existing literature on the subject of trauma and people with a learning disability as outlined in Chapter One. Consideration is given to the strengths and limitations of the research methodology and design, and the study's implications for policy, practice and future research are discussed. Finally, the researcher's self-reflexivity with regards to the entire research process is explored.

Summary of findings

The present study explored the experiences of residential care/support workers who had in their role worked with people with a learning disability who were impacted by trauma or difficult life events. Although care/support workers' experiences of this topic had been previously studied within the UK by McNally et al. (2022), this is the first study to solely focus on this staff group rather than including other professionals working in residential care such as managers and specialist practitioners. Additionally, this research builds on McNally et al.'s (2022) by offering a more in-depth exploration of care/support workers' experiences, facilitated by the use of semi-structured interviews.

Using Reflexive Thematic Analysis (Braun & Clark, 2022), five themes were generated, some of which were further broken into subthemes. The five themes were *grappling with meaning of trauma; negotiating relationships as a means to helping;*

encountering and being immersed in distress; space to think is essential and *navigating a dysfunctional and harmful system.*

Grappling with the meaning of trauma describes care/support workers' attempts to understand how trauma impacted on the people they cared for. It is split into two subthemes – *understanding the way people are: connecting the past and present* which is focused on how care/support workers made sense of the way people's life experiences were connected to their presentations, and *empathy facilitates authentic understanding,* which describes how empathy and recognition of the humanity of people with a learning disability enabled care/support workers to make these connections.

The second theme, *negotiating relationships as a means to helping* captures how care/support workers viewed the relationship between themselves and people with a learning disability as being the vehicle for healing from trauma, and the challenges of this. It is split into three subthemes: *the endeavour to be relational* describes the qualities care/support workers attempted to bring to the relationship in order for it to be a healing one; *the caring relationship isn't a blank slate* explores the interaction in the interpersonal histories of both care/support workers and residents in the caring relationship and *the power in and the power over* highlights how the importance of the relationship and the inherent imbalance in it placed care/support workers in a powerful position.

The theme of *encountering and being immersed in distress* describes how strongly emotive working with people with a learning disability who are impacted by trauma can be. The subtheme of *the emotional weight of the work* explores the different aspects of the job that care/support workers found distressing, while *needing to cut* *off to cope* captures the felt necessity of detaching emotionally in order to manage the demands of the job.

The fourth theme, *space to think is essential,* describes the need for care/support workers to have space to talk and think about their jobs, given the challenges captured in the previous themes. It explores the variation in the extent to which this was present within services, and how care/support workers attempted to manage in the absence of formal spaces.

The final theme, *navigating a dysfunctional and harmful system,* considers the wider context of care/support work and its impacts on residents and staff. The first subtheme, *trying to work within constraints* is describes the issues within social care that hampered care/support workers' attempts to help traumatised people with a learning disability. The second, *under the shadow of the institution,* contains care/support workers' reflections on the legacy of institutionalisation, and how this was still alive in some people and services.

Relation of study findings to previous literature

The present study adds to the small but growing body of literature focused on exploring the impact of trauma on people with a learning disability, and how health and social care services can best support this group of people. Some of the present study's findings correspond with and deepen findings of existing research. Some areas of contrast with the existing literature are also discussed, as well as relevant theoretical links.

The theme of *grappling with the meaning of trauma* and specifically the subtheme of *understanding the way people are: connecting the past and present* corresponds with previous literature in that it captures the importance of staff working with people with a learning disability being able to understand the impact of trauma (Fraser-Barbour, 2018; Keesler, 2014b; Keesler, 2016; Kildahl et al., 2020a; McNally et al., 2022; Truesdale et al., 2019). Some of challenges in identifying trauma in people with a learning disability described in the present study are also highlighted in existing literature, such as a lack of documented history (Fraser-Barbour, 2018; O’Malley et al., 2019) and people’s communication difficulties making it hard for them to give an account of their experiences (Fraser-Barbour, 2018; Keesler 2014b; Kildahl et al., 2020; McNally et al., 2022; Truesdale et al., 2019). The participants in the present study often interpreted that people with a learning disability were impacted by trauma from their behaviour, particularly in the absence of a narrative of somebody’s experiences, in line with previous research (Keesler, 2014b; Keesler, 2016; Kildahl et al., 2020a; McNally et al., 2022). This also links to Kildahl et al.’s (2020b) finding that exposure to potentially traumatic events is associated with increased behavioural disturbance, especially amongst people assessed as having a more severe learning disability and is also in keeping with the assertion that “that which cannot be spoken will be acted out” (Beail, 2021, p.15). Again, it may be important to caveat that the salience of behaviour as being indicative of trauma may have been related to it being more observable than internal experiences such as flashbacks and nightmares, which relatively few of the present study’s participants mentioned, and because of the primacy of behavioural approaches within learning disability services.

The present study identified a possibility for the impact of trauma to be overlooked and later re-appraised, as in previous research (Fraser-Barbour, 2018; Kildahl et al., 2020a; O’Malley et al., 2020; Truesdale et al., 2019). There were however some differences in what appeared to drive this process of re-appraisal between these studies and the present research. In previous research it was generally when new information about people’s lives came to light that staff were then able to reconsider the meaning of their presentations. For example, this was the focus of Kildahl et al.’s (2020a) research, which explored how inpatient staff re-appraised their understanding of the behaviour of a man with a learning disability upon learning he had been subject to sexual abuse. In the present study however participants spoke about times that they and their colleagues did have access to people’s history but still could not realise its impact, suggesting that while having access to people’s histories is important it may not be entirely sufficient. Rather, it is empathy and recognition of the full humanity of people with a learning disability that enables this, as captured in the subtheme of *empathy facilitates authentic understanding*. If staff cannot access this empathy, then they will not be able understand the people they work with in a full and compassionate way. One theoretical understanding that may offer some insight into this is the psychoanalytic notion of a societal death wish against people with a learning disability (Blackman, 2003; Marks, 1999). If unacceptable aspects of the self are split off and unconsciously projected into people with a learning disability, then it follows that empathy will be blocked.

The second theme of *negotiating relationships as a means to helping* is congruent with previous research in that it identifies the relationship between traumatised people with a learning disability and staff as being of utmost importance (Fraser-Barbour, 2018; Keesler, 2014b; Keesler, 2016; O’Malley et al., 2020; O’Malley et al., 2019; McNally et al., 2022). In the present study the subtheme of *the endeavour to be relational* highlights the value of similar relational qualities such as reliability and consistency (Keesler, 2014b; O’Malley et al., 2020). The importance of people with a learning disability being able to develop trust in staff was also emphasised in both the present study and previous literature (Keesler, 2016; McNally et al., 2022; O’Malley et al., 2020; O’Malley et al., 2019. In considering trust, some previous literature describes how this can be difficult as people with a learning disability bring their previous experiences of being harmed in relationships to their interactions with staff (Fraser-Barbour, 2018; Keesler, 2016; McNally et al., 2022; O’Malley et al., 2020). The subtheme of *the caring relationship isn’t a blank slate* in the present study captures this, but also offers a further understanding that the development of the relationship between people with a learning disability and staff is also influenced by the staff’s relational histories. The notion of transference and countertransference may be applicable here (Jones, 2004), in that both parties are transferring something of a previous relational experience into the present interaction. These findings can also considered in relation to attachment theory, which asserts that our early experiences of relationships provide an internal working model which influences how we relate to others later in life, as well as our representations of ourselves (Bowlby, 1973). Within attachment theory, this is considered to be an adaptive process that gives someone the best possible chance of gaining the care and protection necessary for survival. Residents who are responding to staff as if they are likely to harm them as earlier caregivers did can therefore be considered to be doing so in an attempt to protect themselves from harm, despite the difficulties this may cause. The finding within attachment research that there is a possibility for people with difficult early relational experiences to develop an earned secure working model of attachment through later emotionally supportive relationships (Saunders et al., 2011) may also lend some weight to the importance placed on developing sensitive caring relationships by the care/support workers in the present study.

The final subtheme within the theme of *negotiating relationships as a means to helping* was *the power in and the power over.* This offers further exploration of the importance of considering the power differential between staff and people with a learning disability, which was raised within O'Malley et al.'s (2019) research as being necessary for positive relationships. In keeping with the research of Harrison et al. (2021) which found that many people with a learning disability have limited social networks, the participants in the present study often described people they worked with who had few or no relationships beyond those with professionals. The present study offers some consideration of potential psychological impact of having little control over the quality and longevity of one's relationships, and how that can compound existing distress. The Power Threat Meaning Framework (Johnstone & Boyle, 2018) is perhaps of some relevance here. The lack of power people with a learning disability experience within relationships could be considered to constitute a threat, which they have limited means of negotiating. This may drive some of the attempts to exert control over care/support workers as described by some participants in the present study.

The theme of *encountering and being immersed in distress* adds to the body of literature that explores the impact of working with people with a learning disability who are impacted by trauma on staff. The subtheme of *the emotional weight of the work* describes the risk of care/support workers themselves becoming traumatised through their work, as highlighted by Boamah and Barbee (2022). Some of the particular factors identified by Boamah et al. (2023) as increasing the risk of staff experiencing secondary traumatic stress – facing 'challenging behaviour' and a lack of support in the role – featured heavily in the experiences of participants in the present study. Boamah et al. (2023) also found that staff having had personal traumatic experiences increased their likelihood of experiencing secondary traumatic stress, a link that was not elucidated in the present study. Few participants discussed personal difficult life experiences but those who did spoke more about the benefits of this in increasing their empathy and understanding for people rather than any detrimental impact on themselves, although the two are of course not mutually exclusive.

This theme also links to broader literature on work related stress and the wellbeing of care/support workers such as Ryan et al.'s (2021) scoping review which considered the factors relating to stress amongst care/support workers working in learning disability services. Although Ryan et al.'s (2021) review does not consider the role of trauma, it does cite exposure to 'challenging behaviour' as factor that impacts on care/support workers' wellbeing, which the participants in the present study described and framed as a sequalae of trauma. Other factors cited by Ryan et al. (2021) as contributing to stress included having to work within organisation constraints, which was certainly a feature of the present study. There is less consideration of the emotional impact of working with traumatised people with a learning disability on staff in the existing qualitative literature, although several studies described staff reflecting on their perceived inadequacies in caring for this group of people (Keesler, 2014b; Keesler, 2016; O'Malley et al., 2020; O'Malley et al., 2019; McNally et al., 2022; Truesdale et al. 2019), which was identified as driving feelings of guilt and remorse in the present study.

Ryan et al.'s (2021) review also gives some consideration of the coping styles of care/support workers, and the role they play in stress. They described a coping style termed 'wishful thinking' which involved focusing on what might be pleasing to imagine rather than adopting a more rational but potentially distressing perspective, and was associated with increased stress and emotional exhaustion. This may link to the subtheme of *needing to cut off to cope* which describes how some of the participants denied being emotionally affected by their role, despite the distressing situations they faced. Others acknowledged that they employed emotional detachment out of necessity given the implicit and explicit messages about the unacceptability of being emotionally affected by their work.

Similarly, Storey et al. (2012) found that staff working with people with a learning disability and complex mental health presentations in an assessment and treatment unit heavily relied on disavowing their emotions. Storey et al. (2012) drew on psychoanalytic theory to understand this emotional detachment, considering it to be a defence mechanism, which operates as the feelings evoked by the work are too painful and so are banished from conscious awareness. However, psychoanalytic theory would postulate that these inadmissible feelings remain at work on an unconscious level and continue to have influence on how people behave (Ralph, 2001). Assuming this understanding, Storey et al. (2012) concluded that staff working in such settings should have access to spaces to reflect on their work so they can develop their awareness of their counter-transferential feelings rather acting on them without realising, as did Rye et al. (2021) from their work with people with a learning disability diagnosed with personality disorder. This links with the present study's fourth theme, *space to think is essential.* In highlighting how space to think within the role allows care/support workers to work together more effectively, this theme also supports conclusions drawn elsewhere in the literature about the value of a consistent and joined up approach between staff in supporting traumatised people with a learning disability (Fraser-Barbour, 2018; Keesler, 2014b; Keesler, 2016; O'Malley et al., 2020; O'Malley et al., 2019; Truesdale et al., 2019).

The issues reducing care/support workers' ability to respond effectively to people with a learning disability who are impacted by trauma described in the final theme of *navigating a dysfunctional and harmful system* and its subtheme of *trying to work within constraints* are largely replicative of those described in previous literature. In line with previous research (Fraser-Barbour, 2018; Keesler, 2014b; Keesler, 2016; McNally et al., 2022; O'Malley et al., 2020; O'Malley et al., 2019; Truesdale et al., 2019), staff in the present study described a perceived gap between the training they received in their roles and the needs of the people they were caring for. The present study also described staff shortages and staff turnover, which have previously been identified as a barrier to providing quality care to traumatised people with a learning disability (Fraser-Barbour, 2018; Keesler, 2016; Truesdale et al., 2019). A further area of correspondence to the previous literature is the identification of difficulties arising from the nature of congregate settings, such as the potential for harm where residents with incompatible needs are placed together (Fraser-Barbour, 2018; O'Malley et al., 2020).

Some previous qualitative literature on trauma and people with a learning disability mentions the legacy of treatment in institutions (Keesler, 2016) and this is further developed in the present study in the subtheme of *under the shadow of the institution.* The present study makes clear that for many people with a learning disability moving out of institutions does not mean totally leaving them behind, and indeed, the transition to community settings may be a disorienting one, not in the least because poor care remains a possibility (Johnson & Traustadóttir, 2005). That several participants within the current study reported experiences of encountering abuse within care settings also lends support to conclusions drawn by researchers such as Collins and Murphy (2022) that much still needs to be done to prevent people with a learning disability from being harmed and traumatised within residential services.

Theoretical links can also be drawn between the theme of *navigating a dysfunctional and harmful system* and the Power Threat Meaning Framework (Johnstone & Boyle, 2018) in that this theme makes clear the enormous operation of multiple forms of power over the lives of people with a learning disability. It describes various ways in which people often have little choice and control over their everyday lives in addition to being subject to the misuse of power through experiences of abuse. Ideas around ideological power are also relevant here, as this mistreatment takes place in a wider context of marginalisation and devaluing societal discourses around people with a learning disability. The Power Threat Meaning Framework would conceptualise the psychological distress and ‘challenging behaviour’ described by the participants as being threat responses that function to allow people with a learning disability to survive the threats posed by the negative operation of power in their lives.

Although not to the same extent as people with a learning disability, staff can also be considered to be disempowered by the context of residential services. As described within the final theme, staff are trying to provide care without adequate resource and support and under conditions involving significant threat of harm, including through physical violence. From a Power Threat Meaning Framework perspective, working under such conditions may necessitate the use of threat responses and the emotional suppression staff relied upon in order to function in their roles could be conceptualised in this way. As suggested above, this threat response may become defunct if adequate support for staff is provided – as may those utilised by people with a learning disability if they can reach a sense of safety.

Critique of methodology and design

As aforementioned in Chapter Two, debate exists as to what represents quality in qualitative research and how this can be evaluated (Yadav, 2022). One widely applied set of quality criteria which were influential in the design of the present study are those proposed by Yardley (2000). The four criteria are sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. The present research will now be discussed with reference to these criteria.

Sensitivity to context refers to the extent to which research is undertaken with an awareness of the context it is conducted in. This includes appreciation of the relevant literature and theory on the topic being studied; the sociocultural context surrounding the research and the context of the relationship between the researcher, participants and data collected. This was a strength of the present research. Extensive consideration was given to the existing literature related to the subject of care for people with a learning disability who are impacted by trauma, including the completion of a systematic literature research, as detailed in Chapter One. As the previous section demonstrates, the research connects with and builds upon existing empirical and theoretical literature. Additionally, the research was conducted with sensitivity to the sociocultural context, with events such as the Covid-19 pandemic and the repeated scandals around mistreatment of people with a learning disability within health and social care services in the 20th and 21st centuries being held in mind by the researcher from the inception of the research. Finally, the relationship between the researcher, participants and data was considered throughout, as described in the self-reflexive statement. Including the demographics of the participants also further contextualises the research and issues relating to this will be given further consideration below.

Yardley’s (2000) second criteria is commitment and rigour, which is concerned with the degree to which the researcher has had prolonged and thorough engagement with the research. This was a further strength of the present research. As described in Chapter Two, the researcher immersed themselves in the data by conducting the transcription of the interviews and further repeatedly engaging with the data in a systematic way. The methodological grounding of the research was also given consideration. The analysis was completed over an extended time period to allow for time for reflection and ensure that it was not prematurely closed with only a superficial interpretation of the data (Connelly & Peltzer, 2016).

As has already been highlighted, the research demonstrated a high degree of adherence to the principle of transparency and coherence. Transparency and coherence refers to the level of openness around the method and how the findings have been arrived upon, as well as the degree to which there is fit between the research’s aims, method and findings. This is important because it relates to the power and persuasiveness of any claims made. In the present study the methodological and analytic decisions are described in detail and the researcher’s position with reference to the research is clearly elucidated. In making this explicit, coherence between the research’s aims, method and findings is also demonstrated, strengthening the conclusions of the study.

The final criteria, impact and importance, refers to the utility of the research. This can be on several domains, from the theoretical to more practical. As described above, this is the first research to focus solely on the experiences of residential care/support workers who have supported people with a learning disability who are impacted by trauma. As well as enhancing understanding of the experiences of this particular group, it more generally contributes to understanding of the needs of people with a learning disability who are impacted by trauma. This is important because of the relative paucity of research in this area, despite trauma impacting on the lives of many people with a learning disability, as outlined in Chapter One. The research's impact and importance can also be demonstrated through consideration of its implications for policy and practice; these will be further described below, alongside a plan for dissemination of the research.

A further area that needs to be considered in evaluating the strengths and limitations of the present research is recruitment. This was one of the more challenging aspects of the research, although ultimately the lower end of the target number of participants was reached. As described above, in qualitative research determining what constitutes a sufficient sample size is not entirely straightforward (Malterud et al., 2016). As described in the method section, Malterud et al.'s (2016) concept of information power was used to inform the sample size in the present study. Returning to these criteria, including those that could not be fully evaluated prior to data collection such as quality of the dialogue in the interviews, the sample size appears to have been sufficient for the aims of the study. The interviews gave rich, in-depth accounts of the experiences of residential care/support workers in supporting people with a learning disability who are impacted by trauma, no doubt facilitated by the researcher's own experiences of this topic.

It is also worth considering not only the number of participants but the characteristics of those in the sample and how they relate to the population being studied. The present study had some strengths in this area in that the use of remote interviews allowed people working in different services across the UK to participate. There were a mix of ages, genders and length of experience within the sample. However, there were also limitations in terms of the demographic make-up of the sample. According to The King’s Fund (2024), 26% of the adult social care workforce is from an ethnic minority background and 19% are non-British nationals, meaning both were underrepresented within the present research. Such is a common problem, with factors such as a lack of trust in researchers based on racist and oppressive practices within academia being cited as a barrier for participation (George et al., 2014). It may have been that the criteria of having to have enough fluency in English to participate in an interview was a barrier for some people in this particular study, although one that was difficult to surmount given the limited resources for the research. It is unclear whether there were any other specific contextual factors that influenced the underrepresentation of those from ethnic minority and non-British backgrounds in the present study. One possibility was that taking part in research that invites opportunity to criticise one's employer may have felt particularly risky to those who were dependent on their employment for continuation of their right to remain in the UK, such as those on a Health and Care Worker visa.

Additionally, although information about level of education was not specifically asked about, many participants mentioned that they had or were undertaking degree level study, often with the aspiration of later training to become a health care professional such as a clinical psychologist. The sample therefore appears to be more highly educated than perhaps is representative of care/support workers in general. It may have been that having had more exposure to academia, these participants were more likely to see the benefits of research participation, a factor that has been cited as driving hesitancy amongst social care staff (Brown et al., 2024). It may have been beneficial for the researcher to spend more time building relationships with social care organisations in order to promote the value of research and encourage participation. Furthermore, collaboration with services might have addressed some of the practical barriers potential participants reported as preventing them from participating, such as issues around scheduling of shifts. This being said, attempts were made to contact care providers by email but with a very low response rate. Following up by telephone might have increased the likelihood of a positive response or offered an opportunity for a dialogue around the research but would have been a very time-consuming endeavour for a sole researcher.

A further factor proposed by Brown et al. (2024) as influencing whether social care staff chose to take part in research is the degree to which they perceive the particular research aims as being relevant to their roles. During recruitment the researcher had some informal conversations with potential participants that offered some insight into why people may have chosen not to participate. There were some that stated that they did not think that the people with a learning disability they supported were impacted by trauma, despite this sometimes seeming improbable given the number of individuals they had supported and the prevalence of trauma amongst people with a learning disability. In this vein, the study can perhaps only be considered to represent the experiences of care/support workers who had access to the histories of the people they care for, and would conceptualise them as being traumatic. In designing the research materials, the phrase ‘difficult life event(s)’ was used alongside language around trauma, in the hope of increasing accessibility without being overly prescriptive by listing examples of particular events. It would have perhaps been beneficial to consult with stakeholders from the target population on this aspect of the research as there may have been better ways of framing this that would have encouraged more people to come forward.

A further consideration is whether people may have opted not to come forward to participate in the present study is because of personal experiences of trauma. McNally et al. (2022) described how in their study of the perspectives of residential care staff that several people they approached declined to participate citing personal traumatic experiences. While there were some participants in the current study who did describe difficult personal circumstances, it is possible that others chose not to participate for this reason. Staff may also have opted not to participate due to traumatic or difficult experiences that they have in their roles, such as being assaulted or having to work through the Covid-19 pandemic (Nuttall et al., 2022). This also highlights how the wider context in which the study was conducted may well have influenced recruitment. As described in Chapter One, the social care system is currently under enormous pressure as a culmination of many years of austerity and the Covid-19 pandemic (Baines & Cunningham, 2015; Care Quality Commision, 2022; The King’s Fund, 2024). It is entirely conceivable that staff who are working long hours in very stressful conditions may not have wanted to give up their free time to discuss their jobs, and indeed there were some potential participants who ended up not participating because of issues related to their working hours. Furthermore, as some participants in the present study did reflect, it is painful to consider one's shortcomings, and so if staff were aware that the care they were involved in providing was substandard due to organisational constraints (among other factors) they may not have wanted to discuss this.

Implications of the study

The research identifies some areas of good practice as well as some of the challenges facing care/support workers who are caring for people with a learning disability who are impacted by trauma in residential settings. As a whole, the findings illustrate the complexity of caring for this group of people and a need for support and training given to care/support workers to reflect this. The findings also suggest the need for overhaul within the social care system to be made to support this. The particular practice implications developed from each theme are described below.

The theme of *grappling with the meaning of trauma* suggests a need for care/support workers to be able to recognise the impact of trauma on the people they are caring for. The subtheme of *understanding the way people are: connecting past to present* can be used to make a number of suggestions as to how this can be supported. Firstly, it would be helpful for care/support workers to have access to narratives of the life histories of the people they are caring for and it would perhaps be beneficial for documentation practices within care settings to greater reflect this. Although this is not raised by participants in the present study, previous research into supporting people with a learning disability who have been impacted by trauma has raised the need to balance access to information with the rights of people with a learning disability to privacy (Fraser-Barbour, 2018), and so thoughtful consideration must be given as to what is shared with who, ideally with the preferences of the individual at the centre.

Secondly, care/support workers would benefit from access to training that covers how trauma can affect people with a learning disability so they can better identify this within their roles and make connections between people’s life experiences and presentations. That being said, the participants within the present study appeared to be reasonably adept at this. Although they did not frame it as such, what they were doing could be considered an attempt at psychological formulation in that they were hypothesising and trying to make sense of the difficulties people presented with in light of their experiences (DCP, 2011). This suggests a role for clinical psychologists, for whom formulation is a core competency, within residential services for people with a learning disability. The advantage of this would be that clinical psychologists would be able to draw upon the previously described psychological theories that have value in understanding the impact of trauma on people with a learning disability. A key function of psychological formulation is that it provides a bespoke roadmap for any intervention aimed at reducing distress. The use of psychological formulation in residential services could therefore guide and strengthen existing attempts to do this. Psychological formulation may also be beneficial as it has been cited as increasing empathy, which the present study proposes is crucial through the subtheme of *empathy facilitates authentic understanding*. For instance, Whitton et al. (2016) found that participating in team formulation sessions increased empathy amongst staff working on a secure unit for people with a learning disability, amongst other benefits.

Psychological formulation may also help address some of the challenges raised in the theme of *negotiating relationships as a means to helping*. Firstly, a formulation could make clear what somebody’s unmet needs are in terms of relationships and reinforce the importance of the qualities described in the subtheme of *the endeavour to be relational.* Secondly, formulation could help inform understanding of some of the interpersonal dynamics described in the subthemes of *the caring relationship isn’t a blank slate* and *the power in and the power over.* There again may be a role for training here, with an emphasis on increasing awareness of how trauma can impact on interpersonal relationships. One pre-existing package of training that may be particularly helpful here is Rye et al.'s (2021) CaPDID, which as described above focuses using psychoanalytic concepts to encourage care staff to reflect on their own feelings and behaviours when working with this client group.

Beyond formulation and training, the theme of *negotiating relationships as a means to helping* suggests that services ought to be run in ways that prioritise the formation and maintenance of supportive relationships between care/support workers and residents. People with a learning disability who are impacted by trauma may particularly benefit from being supported by a consistent staff team and rotas should reflect this. Moreover, staffing levels should be determined based on what allows for people's emotional as well as practical needs to be met. This theme also makes clear the need for measures to be taken to reduce staff turnover within social care; this will be further considered under the theme of *navigating a dysfunctional and harmful system.* Whether or not retention of staff within social care improves, care/support workers will inevitably always leave their roles. The present research suggests the need for the impact of this on traumatised people with a learning disability to be considered. People may benefit from advance notice and clear explanations as to when and why staff are leaving, so that it is not experienced as another abandonment or rejection.

The theme of *encountering and being immersed in distress* suggests the need for more support for care/support workers given the emotional demands of their roles. In the subtheme *the emotional weight of the work* the possibility for care/support workers to become traumatised themselves through working with people with a learning disability was raised. This included through directly encountering potentially traumatic experiences as part of their role such as violence or self-harm and secondary traumatisation through repeated exposure to accounts of people's trauma experiences. A recent scoping review which aimed to explore the benefits of interventions aimed at reducing the impact of secondary trauma amongst health and social care service providers found some benefit in interventions such as psychoeducation and mindfulness (Kim et al., 2022). Its authors were critical of claims made by many of the studies included in their review however, and suggested the benefits derived from these interventions may have been more to do with reducing general stress levels than specifically targeting the impact of secondary trauma, suggesting the need for further research into how this specifically can be addressed.

In October 2020, in response to the Covid-19 pandemic, nationally funded staff mental health and wellbeing hubs were commissioned for health and social care staff in recognition of the demands of these roles during this period (NHS England, 2024). These hubs provided valuable specialist support to staff, including access to psychological therapies (Allsopp et al., 2022). However, since the peak of the pandemic and the withdrawal of central funding many of these services have been decommissioned (BPS, 2023). The present study suggests however that there remains a great need for access to such specialist support for social care staff. Greater support for staff would perhaps reduce the need for care/support workers to rely on emotional detachment to manage their roles, as captured in the subtheme *needing to cut off to cope,* hopefully reducing burnout. The subtheme of *needing to cut off for cope* also suggests the need for a cultural shift within social care services around attitudes to staff distress. This is supported by research by Keyworth et al. (2022) which found that both peers and senior colleagues being open about the possibility and value of support was a factor that enabled staff to access their local staff wellbeing hub. Keyworth et al. (2022) also highlighted the benefits of staff being able to seek confidential support away from their workplace. This might have also been helpful for the participants in the present study who may have found it hard to acknowledge their own distress.

The fourth theme, *space to think is essential,* also highlights the need for greater support for care/support workers, given the demands and complexity of their roles. The few participants who had access to regular supervision and reflective practice sessions reported these as being valuable because they afforded an opportunity to step back, think and talk about the work they were doing. If one adopts a psychoanalytic perspective, this is vital for preventing problematic dynamics from being acted out between staff and residents, as well as reducing staff distress (Rye et al., 2021; Storey et al., 2012). This may be another area where clinical psychologists could support the running of residential services. There may be some particular value in having someone outside of the direct care team facilitating supervision and reflective practice in order to offer a different perspective. Having the team together for reflective practice may also offer an opportunity for staff to learn from and support one another. It was clear that the participants in the present study valued peer support, and opportunities for this within care settings should be encouraged. It should be kept in mind however that there is not excessive burden placed on more experienced and senior care/support workers to provide support without being supported themselves, given they are likely facing the same challenging situations. Of course, for space to think to be embedded within care settings, consideration needs to be given as to how care/support workers can be released from directly providing care for long enough to have uninterrupted time to reflect on their work.

The final theme of *navigating a dysfunctional and harmful system* suggests that systemic changes need to be made within the social care system for people with a learning disability who are impacted by trauma to be better supported. Within the subtheme of *trying to work within constraints,* participants reflected on the need for the status of care work as an unskilled job to be re-evaluated. Again, this suggests the need for further training to be offered to care/support workers to prepare them for the complexities of supporting people with a learning disability who are impacted by trauma. This may be in addition to existing packages of training, such as PBS, which participants generally reported valuing in guiding how to respond to ‘challenging behaviour’ but having limitations in addressing trauma. That being said, trauma-informed approaches to PBS have been developed (Harding, 2021) and their implementation may help bridge this perceived gap in efficacy. Moreover, consideration needs to be given to what extent it is the role of support workers to address the effects of trauma. Beyond this, people with a learning disability may require access to specialist treatments such as psychological therapies. Many of the participants reported advocating for the people they cared for to receive such interventions with little success, and there was a sense that they were left working beyond their own expertise without this. Based on this, it seems important for there to be greater collaboration between health care professionals and social care services. Of course, this is supposed to be a function provided by NHS Community Learning Disability Teams but perhaps within the current context of resource scarcity this isn’t always happening effectively.

The undervaluing of care/support workers was also described as manifesting in poor working conditions, such as low pay and long unsocial hours. Given the importance of consistency and sufficient numbers of staff for provided trauma sensitive care, and the current crisis in recruitment and retention, more needs to be done to improve working conditions in order to make working within social care more attractive. Pay has been cited as a factor that strongly influences whether social care staff in learning disability services stay in their roles (Murray et al., 2022). Interestingly, the only factor that superseded pay in influencing staff retention was the quality of relationship between staff and residents, further suggesting the benefits of services placing emphasis on supporting the development of positive relationships. If staff retention improves within social care services, then recruitment practices within social care will be able to more thoughtfully consider to what extent people are suited to the role before hiring them. This is important as it is not only the quantity of staff that matters but their quality, given the issue raised by several participants of the detrimental impact on residents of care/support workers not taking the responsibilities of their job seriously.

The research raises issues relating to the suitability of some residential care environments for people with a learning disability who are impacted by trauma. The majority of participants described working in congregate settings, which raised challenges as in general people had not chosen to live with one another, and there did not seem to be much consideration of the impact that residents may have had on one another, for instance people with a history of being subject to interpersonal violence living with people with aggressive behaviour. A more individualised approach to the planning and commissioning of social care placements appears pertinent here. The subtheme of *under the shadow of the institution* further describes a continued lack of individualised care in some learning disability services. Several participants within the sample also described encountering abusive care practices in their work, which they went on to report. The abuse the participants described often appeared to have been sustained over a period of time prior to being discovered, suggesting that multiple care/support workers were either directly involved or had witnessed it and not spoken out. This raises the point that current safeguarding measures are not adequate, and more needs to be done to protect people with a learning disability from abuse in residential care settings. To return to research by Collins and Murphy (2022) on factors that are predictive of abuse within residential settings, they found that poor training, lack of supervision, high staff turnover and staff shortages were contributory factors. This suggests that the recommendations of the present study, if implemented, may have some benefits in preventing abuse from happening in the first place, as well as improving care for people with a learning disability who are already impacted by trauma.

To summarise the recommendations, care/support workers in residential services need better access to training, supervision and reflective spaces in order to support their work with people with a learning disability who are impacted by trauma. This would facilitate the provision of individualised care that accounts for the impact of people’s life experiences; prioritises the development and maintenance of safe and therapeutic relationships and reduces the likelihood of people with a learning disability being further harmed. The proposed improvements heavily align with the key assumptions and principles of trauma informed care (Goad, 2022; Huang et al., 2014; McNally et al., 2023), suggesting its applicability to learning disability services. It is clear that for such an approach to be implemented systemic changes need to be made within social care to support this and this would involve significant financial investment. This is likely to be challenging in the current climate of austerity (Baines & Cunningham, 2015). With many local authorities struggling to maintain the delivery of social care services as they are because of budget deficits (The King's Fund, 2024), a radical shift in the way social care is funded may therefore be necessary for improvements to be made.

The impact of trauma has to date been largely overlooked in major UK policy relevant to the lives of people with a learning disability (Department of Health, 2001; Department of Health and Social Care, 2010; 2022). Although much policy has been developed in reaction to scandals around mistreatment of people with a learning disability, particularly within hospital settings (Department of Health and Social Care, 2022) how people can be supported in the aftermath of such treatment and others traumas is notably absent. The present study makes it clear that trauma needs to be more on the agenda in policy relating to the health and social care needs of people with a learning disability, as it is starting to be in other areas of health and social care, such as mental health services (NHS Confederation, 2019; Morris, 2021). Of course, many of the principles outlined in current UK policy, such as for safe and individualised care that affords people with a learning disability as much choice and control over their own lives as possible (Department of Health and Social Care, 2010; 2022), are already compatible with the TIAs outlined in the present study. Making the need for trauma sensitive care for people with a learning disability explicit in policy would however raise awareness of these issues and hopefully encourage funders and providers to implement some of the recommendations for practice outlined above.

The present study contributes to a small but growing evidence base around the support needs of people with a learning disability who are impacted by trauma.

Based on the present study directions for future research can be identified, both to address its limitations and to build on its conclusions. As described above, the present study aimed to examine the experiences of care/support workers who had supported people with a learning disability who were impacted by trauma. The study’s design meant that participation in the research was predicated on care/support workers being aware that the people they cared for had been affected by such experiences; therefore the experiences of other care/support workers who did not have this understanding were not represented. It may be helpful therefore for future research to capture the views of this group of care/support workers in order to further understand what some of the barriers to them being aware of and responsive to trauma are. Of course, this presents a challenge as to how you recruit people to take part in research focused on an experience they are not aware that they have. One potential way of addressing this could be approaching service managers or NHS Community Learning Disability Teams to identify services in which people with a learning disability who have a trauma history reside. Care/support workers from these services could then be invited to participate in interviews about their more general experiences of providing care and how they understand any difficulties.

Alternatively, research could invite care/support workers to participate in interviews about working with people with a learning disability who have been exposed to specific types of traumatic experiences, as it may easier for people to assess whether a particular event has occurred in someone’s life than whether their experiences fit into the more abstract category of trauma. As well as perhaps encouraging a broader range of people to participate in research about trauma, this would allow for understanding to be developed as to whether there are nuances in support needs according to different types of difficult life experiences. For example, many participants in the present study spoke about the impact of bereavement on people with a learning disability. While often the way that bereavement in people with a learning disability is responded to compounds distress (Blackman, 2003), loss is a normal and inevitable part of life. It therefore does not seem implausible that the support needs associated with this might be different from those resulting from an experience of interpersonal abuse which involves deliberate mistreatment.

As previously explored, the present study is in line with previous research in that it acknowledges the possibility for care/support workers to become distressed by their roles and affected by secondary traumatisation (Boamah & Barbee, 2022; Boamah et al., 2023). Further research is needed as to how this can be prevented and ameliorated within social care staff working with traumatised people with a learning disability. This could include evaluating how the recommendations of the present study for increased support for care/support workers impact on their wellbeing, as Boamah et al. (2023) found that staff who reported being unsupported in their role were more likely to experience secondary traumatisation. The impact of increased support for care/support workers could also be evaluated in terms of whether it reduces staff turnover, given the importance of this for the delivery of quality care.

The recommendations of the current study and TIAs should also be evaluated in terms of their impact on people with a learning disability living in residential care, with consideration given to how best to assess their impact. Much of the existing literature evaluating interventions in learning disability services, such as that on PBS, focuses on levels of ‘challenging behaviour’ rather than other outcomes such as quality of life (MacDonald & McGill, 2013). Further qualitative research which aims to capture the views and experiences of people with a learning disability who live in residential services on their care would also be valuable, with consideration given to using inclusive research methods so that people with a learning disability who may struggle to articulate themselves verbally can also have their perspectives represented (Cluley, 2017). It is essential that future research considers the ethical dilemmas relating to people with a learning disability participating in research (Goldsmith & Skirton, 2015), as well as the ethics of excluding people with a learning disability from research participation, as the result is that people with a learning disability have less opportunity to have a say about matters impacting on their own lives (Juritzen et al., 2011).

Of course, the degree to which the implications of the present study can be realised is contingent on the research being appropriately disseminated. After the completion of the thesis and viva, the researcher will seek to write up the results of this study in the appropriate format for publication in an academic journal. There are various journals that could be approached to publish this research. Some similar research has been published in learning disability focused journals, such as the Journal of Applied Research in Intellectual Disability, the Journal of Policy and Practice in Intellectual Disabilities and the British Journal of Learning Disabilities. Alternatively, publication in a trauma related journal such as the Journal of Trauma, Violence and Abuse could be pursued. Opportunities to present the research at a relevant conference will also be sought. To promote dissemination of the research outside of academia and hopefully broaden its reach, consideration will also be given to approaching local commissioners of residential care services for people with a learning disability.

Self-reflexivity

Initially I had hoped to conduct some research directly with people with a learning disability around their experiences of support following trauma. It felt important to me that their voices should be prioritised given the importance of regaining autonomy in the aftermath of trauma. Although I experienced some disappointment about being unable to find a way to do this in a way that was ethical and also fit in with the constraints of my studies, I was able to become passionate about this research and felt proud to see it through to completion. I had little research experience prior to completing my doctorate, having used pre-existing data for my undergraduate project, and have learnt a lot about the research process. In particular, I have developed my skills in research interviewing and how this differs from clinical interviewing, and in qualitative data analysis. I hope that I am able to be involved in further research post-qualification and perhaps that one day I might be able to conduct research to amplify the voices of people with a learning disability.

As described in my self-reflexive statement in Chapter Two, I have previously worked as a support worker with people with a learning disability and considered these experiences throughout the research. I recognised much of what participants were saying – working long hours in emotionally demanding and threatening circumstances with very little support. I found myself being pleasantly surprised at times when some participants spoke about being supported and have tried to capture these experiences within the analysis. I have continued to work clinically while completing the research, including spending a year in learning disability services while I was collecting the data. In doing this I have often thought about the reciprocal relationship between my research and clinical practice. For instance, when

I have run training and case discussion sessions for care/support workers, I have held in mind how difficult it might be for them to acknowledge how they feel about the work they are doing. I have also encountered in my clinical practice some staff who were not able to recognise trauma and though for obvious reasons those people didn’t take part in my research, I used these experiences to influence some of my questioning about what helped the participants to recognise trauma while some of their colleagues did not.

Conducting the research was at times an emotive experience, although not for the reasons I thought it might be. I anticipated the possibility that I may become distressed by accounts of the trauma experienced by people with a learning disability and to some extent I did - I think some of the stories I have chosen to illustrate my analysis were those I found particularly emotionally affecting. However, what I actually found most emotive were some of the more subtle ways that people with a learning disability were harmed, for instance when participants spoke about having colleagues who would perhaps minimise the distress people experienced. I felt powerless and guilty in these situations because I felt I could do nothing to change it and while it was not the sort of mistreatment that would reach threshold for a safeguarding concern, I still felt that it had a negative effect on people and this does matter. I found supervision helpful to allow me space to think about the conflict I felt here, of wanting to take action to make things better but not being able to. I think this in particular has motivated me to pursue publication of my research and further knowledge about the needs and issues facing traumatised people with a learning disability and those who care for them. I really hope that if I can do this, the research can be used to improve practice even in some small way. It has certainly influenced the way that I practice as an almost qualified clinical psychologist, and I have definitely benefitted from conducting the research.

Conclusion

To conclude, this research makes a novel contribution to the body of research concerned with needs of people with a learning disability who are impacted by trauma. Specifically, it is the first study to offer an in-depth exploration of residential care/support workers' experiences of supporting this group of people within a UK context. Reflexive Thematic Analysis was used to generate five themes and nine subthemes which explored how care/support workers endeavoured to understand and care for traumatised people with a learning disability, and the challenges they faced in doing so, with directions for improvement to policy and practice and future research suggested based on these findings.

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Appendices

Appendix A – Quality appraisal with CASP checklist for qualitative research (CASP, 2018)

Author	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	Overall judgement of quality
Fraser-Barbour (2018)	**Yes.** Clearly stated within introduction section of paper.	**Yes.** Aim of study is to explore participants' views and experiences.	**Can't tell.** The method section does not contain details of how the method was arrived upon.	**Yes.** Participants with relevant experience were recruited purposively.	**Yes.** Data collection method and decisions around this are detailed in method section of the paper.	**Can't tell.** There is no discussion within the paper of the potential effect of the researcher on the participants.	**Can't tell.** Details are very scant and discussion of ethical issues is limited to a single sentence.	**Can't tell.** There are some strengths - approach to analysis is outlined clearly; data is used to illustrate findings and contradictory data is explored. However, there is no detail around consideration of the researcher's own role in analysing the data.	**Yes.** The findings section is clear and the findings are discussed with regards to the research question in the discussion section.	The results are valuable. They are considered in relation to the existing literature and policy and practice implications are thoroughly explored in the discussion section.	**Moderate**
Keesler, 2014	**Yes.** Clearly stated within introduction section of the paper.	**Yes.** Aim of study is to explore participants' views and experiences	**Can't tell.** The method section does not contain details of how the method	**Yes.** Participants with relevant experience were recruited purposively.	**Yes.** Data collection method and decisions around this are detailed in	**Can't tell.** The researcher includes that the services participants worked in were known	**Yes.** Potential ethical issues and decisions made around these, including review by an ethics	**Can't tell.** Some rigour is demonstrated through reporting of details around the approach to	**Yes.** The findings section is clear and the findings are discussed	The results are valuable. They are considered in relation to the existing	**Moderate**

			was arrived upon.		method section of the paper.	to him, however, the potential impact of this is not explored.	committee, are discussed within the method section of the paper.	analysis and the steps taken during analysis to ensure its quality. However, there is no consideration of the role of the researcher.	with regards to the research question in the discussion section.	literature. However, no implications for policy and practice deriving from the results of the study are suggested.	
Keesler, 2016	**Yes.** Clearly stated within introduction section of the paper.	**Yes.** Aim of study is to explore participants' views and experiences	**Yes.** There is some discussion of how the research design was arrived upon in order to meet the aims of the study.	**Yes.** Participants with relevant experience were recruited purposively.	**Yes.** Data collection method and decisions around this are detailed in method section of the paper.	**Can't tell.** The researcher does state that their extensive knowledge on the subject at hand may have influenced his approach to the research, however, he does not explicitly explore how this might have impacted on his relationship with the participants.	**Can't tell.** Other than stating that informed consent was obtained, no details around how ethical issues were addressed is included. There is no statement indicating that the study received ethical approval from an ethics committee.	**Can't tell.** Some rigour is demonstrated through reporting of details around the approach to analysis and the steps taken during analysis to ensure its quality. However, there is no consideration of the role of the researcher.	**Yes.** The findings section is clear and the findings are discussed with regards to the research question in the discussion section.	The results are valuable. They are considered in relation to the existing literature. However, no implications for policy and practice deriving from the results of the study are suggested.	**Moderate**
Kildahl et al., 2020	**Yes.**	**Yes.**	**Yes.**	**Yes.**	**Yes.**	**Can't tell.**	**Can't tell.**	**Can't tell.**	**Yes.**		**Moderate**

	Clearly stated within introduction section of the paper.	Aim of study is to explore participants’ views and experiences	There is some discussion of how the research design was arrived upon in order to meet the aims of the study.	Participants with relevant experience were recruited purposively.	Data collection method and decisions around this are detailed in method section of the paper.	The authors outline their relationship to the service where the participants worked, however, they do not explore the potential impact of this relationship on their participants.	Confirmation is given that the study was subject to ethical approval. However, other than stating that informed consent was provided, there is little discussion of pertinent ethical issues.	Some rigour is demonstrated through reporting of details around the approach to analysis and the steps taken during analysis to ensure its quality. However, there is no consideration of the role of the researcher.	The findings section is clear and the findings are discussed with regards to the research question in the discussion section.	The results are valuable. They are considered in relation to the existing literature and policy and practice implications are thoroughly explored in the discussion section.	
McNally et al., 2022	**Yes.** Clearly stated within introduction section of paper.	**Yes.** Aim of study is to explore participants’ views and experiences.	**Yes.** There is some discussion of how the research design was arrived upon in order to meet the aims of the study.	**Yes.** Participants with relevant experience were recruited purposively.	**Yes.** Data collection method and decisions around this are detailed in method section of the paper.	**Can’t tell.** There is no discussion within the paper of the potential effect of the researcher on the participants.	**Can’t tell.** Few details are provided around how ethical issues are addressed, beyond a statement confirming the research had received approval from an ethics committee.	**Can’t tell.** Some rigour is demonstrated through reporting of details around the approach to analysis and the steps taken during analysis to ensure its quality. However, there is no consideration of the role of the researcher.	**Yes.** The findings section is clear and the findings are discussed with regards to the research question in the discussion section.	The results are valuable. They are considered in relation to the existing literature and policy and practice implications are thoroughly explored in the discussion section.	**Moderate**

O'Malley et al. (2020)	**Yes.** Clearly stated within introduction section of paper.	**Yes.** Aim of study is to explore participants' views and experiences.	**Yes.** There is some discussion of how the research design was arrived upon in order to meet the aims of the study.	**Yes.** Participants with relevant experience were recruited purposively.	**Yes.** Data collection method and decisions around this are detailed in method section of the paper.	**Can't tell.** There is no discussion within the paper of the potential effect of the researcher on the participants.	**Can't tell.** Few details are provided around how ethical issues are addressed, beyond a statement confirming the research had received approval from an ethics committee.	**Can't tell.** Some rigour is demonstrated through reporting of details around the approach to analysis and the steps taken during analysis to ensure its quality. However, there is no consideration of the role of the researcher.	**Yes.** The findings section is clear and the findings are discussed with regards to the research question in the discussion section.	The results are valuable. They are considered in relation to the existing literature and policy and practice implications are thoroughly explored in the discussion section.	**Moderate**
O'Malley et al. (2019)	**Yes.** Clearly stated within introduction section of paper.	**Yes.** Aim of study is to explore participants' views and experiences.	**Yes.** There is some discussion of how the research design was arrived upon in order to meet the aims of the study.	**Yes.** Participants with relevant experience were recruited purposively.	**Yes.** Data collection method and decisions around this are detailed in method section of the paper.	**Yes.** There is some discussion of the relationship between the researcher and the participants, such as how the researcher was introduced to potential participants.	**Yes.** There is a high level of detail around how ethical issues were addressed, particularly obtaining informed consent and protecting the anonymity of potentially vulnerable participants.	**Yes.** Rigour is demonstrated through reporting of details around the approach to analysis and the steps taken during analysis to ensure its quality. The researcher makes explicit how they considered their own role	**Yes.** The findings section is clear and the findings are discussed with regards to the research question in the discussion section.	The results are valuable. They are considered in relation to the existing literature and policy and practice implications are thoroughly explored in the discussion section.	**High**

								in analysing the data through engaging in regular supervision and reflection.			
Truesdale et al., 2019	**Yes.** Clearly stated within introduction section of paper.	**Yes.** Aim of study is to explore participants' views and experiences.	**Yes.** There is some discussion of how the research design was arrived upon in order to meet the aims of the study.	**Yes.** Participants with relevant experience were recruited purposively.	**Yes.** Data collection method and decisions around this are detailed in method section of the paper.	**Can't tell.** There is no discussion within the paper of the potential effect of the researcher on the participants.	**Can't tell.** There is confirmation that the research was subject to ethical approval. Discussion of ethical considerations could be more extensive as other than stating that informed consent was obtained and participants were assured of their anonymity there are few details provided.	**Can't tell.** Some rigour is demonstrated through reporting of details around the approach to analysis and the steps taken during analysis to ensure its quality. However, there is no consideration of the role of the researcher.	**Yes.** The findings section is clear and the findings are discussed with regards to the research question in the discussion section.	The results are valuable. They are considered in relation to the existing literature and policy and practice implications are thoroughly explored in the discussion section.	**Moderate**

Appendix B – Study Interview Guide

Interview Guide

Introduction

- Restate the purpose of study
- Discuss the previously provided information, particularly the potential for participant distress; where participants can seek further support if they are distressed; the likelihood that doing the interview will not directly benefit the participant; the right to decline or stop the interview; confidentiality and its limits.
- Confirm that the participant is willing to go ahead with the interview
- Ask demographic and background questions
- How old are you?
- How would you describe your gender identity?
- How would you describe your ethnicity?
- How would you describe your nationality?
- How many years' experience do you have working in residential care with adults with a learning disability?

Begin interview: "I would like to hear about your experiences of working in a residential care service with an adult with a learning disability who has had a difficult life experience."

Topic 1: What kinds of difficult experiences did you see as having an impact on people, and what was that impact?

Potential prompt questions:

- What was the impact at the time of the experience?
- How did the experience affect the person over time?
- How did you learn about the experience?
- How did you know the experience was affecting the person?
- Further questions about its impact – emotional, behavioural, physical, social/interpersonal
- How did the person try to cope with the experience?
-

Topic 2: How did you respond?

Potential prompt questions

- (If the event they described happened while they knew the person) how did you respond when the event happened?
- How did you respond to their distress over time?
- (If the event was disclosed by the person) how did you respond when they told you?
- How did learning about the experience change how you worked with the person?
- What influenced how you responded to the person?
- Did you get any support from other people/services?
- Were there things that made it difficult to support the person?

Topic 3: What was the impact of how you responded?

- Was there anything that changed for the person as a result of this support?
- Was there anything that seemed to make things worse?
- What was the impact of working with this person on you?

“Is there anything else you would like to add?”

Debrief

- Check with participants how they are feeling and reiterate options for further support
- Offer participants a chance to ask further questions
- Ensure participants have my details and reiterate right to withdraw data up to a week after
- Thank participants for their time

Appendix C – Recruitment advertisement

Have you worked in a residential care setting with adults with a learning disability?

Has someone you supported experienced a difficult life event?

Do you want to share your experiences in a research study?

My name is Katie Sydney. I used to work as a support worker with adults with a learning disability and I am currently a Trainee Clinical Psychologist at the University of Essex. As part of my doctoral thesis, I am looking to talk to:

- Adults (over the age of 18)
- Who have been employed as a care/support worker in a residential setting for people with a learning disability for at least 6 months in the past 3 years
- Who have in this role supported someone who has disclosed or been identified as experiencing a difficult life event
- Who do **not** hold registration as a health care professional

About their experiences of working with people with a learning disability who have been impacted by a difficult or traumatising life event.

If you are interested in taking part or finding out more about the research, please contact the researcher by email on ks21965@essex.ac.uk or telephone on 07546802942 to discuss.

This research is being supervised by Dr John Day and Dr Danny Taggart.

What will happen if I take part in the research?

- Participation in the study is voluntary. If you agree to take part, you will be interviewed by the researcher about your experiences. This will last around an hour
- This interview will be audio recorded. All data collected will be stored securely and will be anonymised before being used in any publication

What are the risks and benefits of taking part?

Due to the focus of the study, it is possible that participants may find participating distressing. There may not be any direct benefits in taking part but it is hoped that the findings could help to improve services for people with a learning disability, and support for the staff who work in them.

This study has received approval from the University of Essex Ethics Committee. The reference number is ETH2324-0018.

University of Essex

Appendix D – Information Sheet

Residential care staff's experience of supporting adults with a learning disability impacted by trauma

Participant Information Sheet (V2)

My name is Katie Sydney and I am a Trainee Clinical Psychologist at the University of Essex. I would like to invite you to take part in a research study, which I am conducting as part of my professional Doctorate in Clinical Psychology. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

This research aims to find out about residential care/support staff's experiences of working with adults with a learning disability who have experienced traumatising or difficult life events. It is hoped that the study findings will contribute to the development of trauma informed care for people with a learning disability.

Why have I been invited to participate?

You have been invited to participate because you have been employed as a care/support worker in a residential setting, for a minimum of 6 months in the past 3 years. During this time you will have worked with an adult with a learning disability who has disclosed or been identified as having experienced a difficult or traumatising life event.

What will happen to me if I take part?

You will meet with the researcher (either in person or by video/telephone call) for an interview. The interview will last approximately one hour. You will have the chance to ask questions and discuss the research before deciding whether or not to take part.

You will be asked some demographic questions. You will then be asked some questions about your experience working with adults with a learning disability who have disclosed or been identified as having experienced a difficult or traumatising life event. The interviews will be audio recorded.

Do I have to take part?

Taking part in the research is entirely voluntary. You can stop the interview at any time for whatever reason and without explanation or penalty. You can request your data is not used in the analysis or write up for up to one week post interview, after which point it will not be possible to withdraw.

What are the possible disadvantages and risks of taking part?

The research is concerned with a sensitive topic which you may find distressing to discuss.

What are the possible benefits of taking part?

By taking part in this study your knowledge and expertise can be represented in research. This could help improve services for people with a learning disability, and support for staff working in these settings. This is not a guarantee however and there may be no direct benefits of taking part.

Will my information be kept confidential?

Participation in the study will be kept confidential. The exception to this would be if you disclose information that suggests you or another person is at risk of harm.

Your data will be stored electronically in secure, password protected files. Your contact information and consent forms with your name on will be stored separately to the interview data, which will be assigned a pseudonym. The audio recordings of the interviews will be deleted after they have been transcribed. The data will only be accessed by myself and my supervisors. The data will be retained for up to 10 years and then it will be deleted. The legal basis for processing the data is your consent.

Your data will be stored in accordance with the principles of GDPR. The Data Controller is the University of Essex University Information Assurance Manager, who you can contact on dpo@essex.ac.uk.

What will happen to the results of the research study?

The results of the research will be written up as part the principle investigator's doctoral thesis. This will be retained in the University of Essex thesis repository. It may also be published in a relevant academic journal.

What should I do if I want to take part?

If you would like to take part in this study, or ask further questions, please contact Katie Sydney on ks21965@essex.ac.uk or 07546802942.

Who has reviewed the study?

This study has been granted ethical approval by the University of Essex Research Ethics Sub-Committee 2.

Who should I contact if I have concerns?

If you have any concerns about any aspect of the study or you have a complaint, in the first instance please contact the principal investigator of the project, Katie Sydney, using the contact details above. You can also contact either of Katie's supervisors – Dr John Day (john.day@essex.ac.uk) or Dr Danny Taggart (dtaggart@essex.ac.uk). If you are still concerned, you think your complaint has not been addressed to your satisfaction or you feel that you cannot approach the principal investigator, please contact Professor Camille Cronin, the departmental director of research for the School of Health and Social Care (camille.cronin@essex.ac.uk), and then Sarah Manning-Press (sarahm@essex.ac.uk), the Research Governance and Planning Manager. Please include the ERAMS reference which can be found at the foot of this page.

Where can I get support if I feel affected by the issues raised by the study?

Health and social care staff working in England can self-refer to their local Staff Mental Health and Wellbeing Hub, details of which can be found at https://www.england.nhs.uk/supporting-our-nhs-people/support-now/staff-mental-health-and-wellbeing-hubs/.

Samaritans is a free, confidential listening service available 24/7 all year round. They can be contacted by telephone on 116 123, or you can visit their website at https://www.samaritans.org/.

Appendix E – Consent Form

Residential care staff's experiences of supporting adults with a learning disability impacted by trauma

Consent Form (V2)

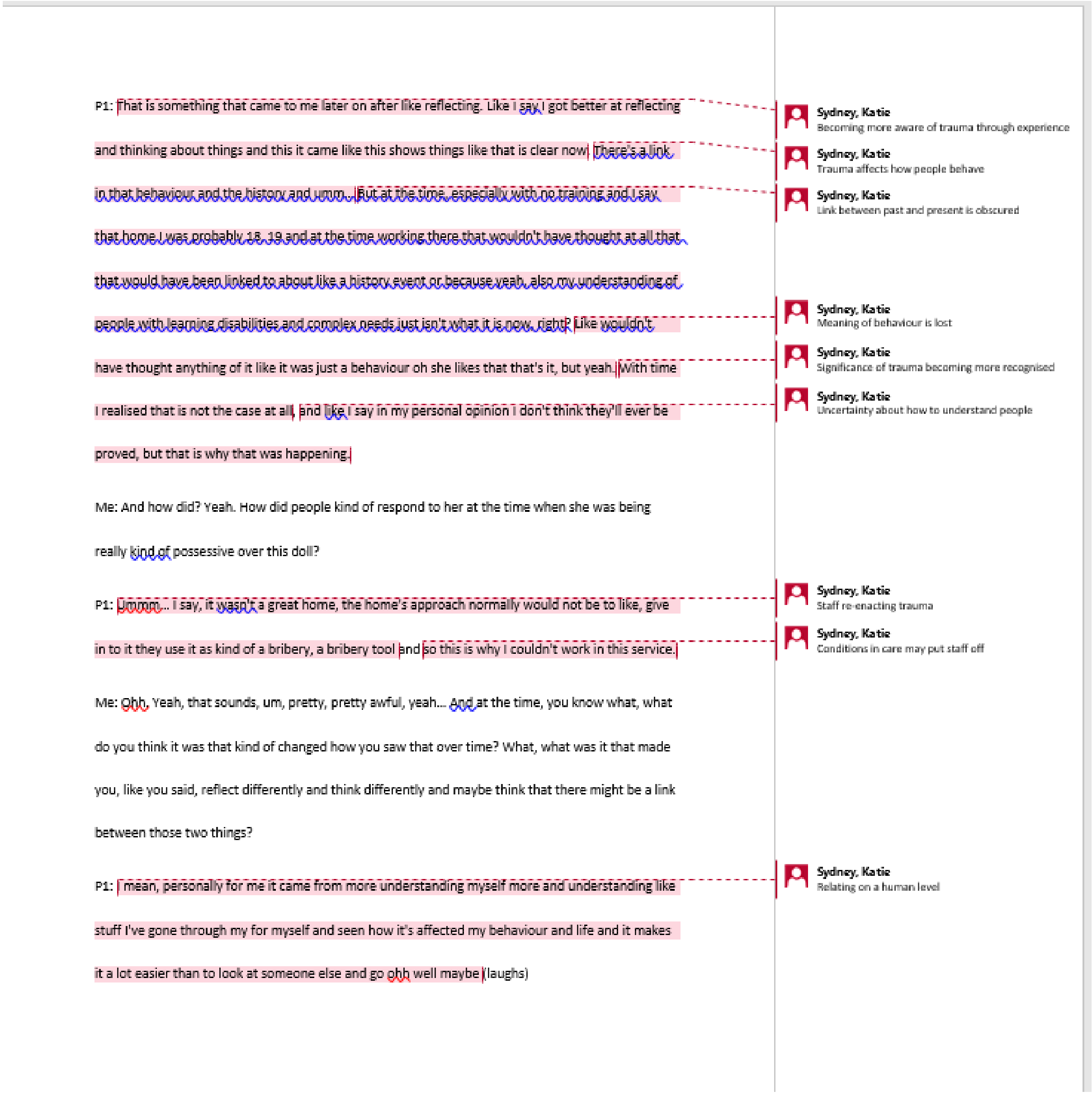
Please initial box

1. I confirm that I have read and understand the Information Sheet dated 20/12/2022 for the above study. I have had an opportunity to consider the information, ask questions and have had these questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the project until one week after the interview has passed without giving any reason and without penalty. I understand that any data collected up to the point of my withdrawal will be destroyed. ☐
3. I understand that the research is focused on a potentially sensitive subject, and I may find being asked questions around it uncomfortable or distressing. ☐
4. I understand that the identifiable data provided will be securely stored for up to ten years and accessible only to the members of the research team directly involved in the project, and that confidentiality will be maintained. ☐
5. I understand that my fully anonymised data will be used in the researcher's doctoral thesis and potentially for publication in a research journal ☐
6. I agree to take part in the above study. ☐

Participant Name	Date	Participant Signature
______________________	__________	______________________

Researcher Name	Date	Researcher Signature
______________________	__________	______________________

Appendix F – Example Coded Extract of Interview



P1: That is something that came to me later on after like reflecting. Like I say I got better at reflecting and thinking about things and this it came like this shows things like that is clear now. There's a link in that behaviour and the history and umm... But at the time, especially with no training and I say that home I was probably 18, 19 and at the time working there that wouldn't have thought at all that that would have been linked to about like a history event or because yeah, also my understanding of people with learning disabilities and complex needs just isn't what it is now, right? Like wouldn't have thought anything of it like it was just a behaviour oh she likes that that's it, but yeah. With time I realised that is not the case at all, and like I say in my personal opinion I don't think they'll ever be proved, but that is why that was happening.

Me: And how did? Yeah. How did people kind of respond to her at the time when she was being really kind of possessive over this doll?

P1: Ummm... I say, it wasn't a great home, the home's approach normally would not be to like, give in to it they use it as kind of a bribery, a bribery tool and so this is why I couldn't work in this service.

Me: Ohh, Yeah, that sounds, um, pretty, pretty awful, yeah... And at the time, you know what, what do you think it was that kind of changed how you saw that over time? What, what was it that made you, like you said, reflect differently and think differently and maybe think that there might be a link between those two things?

P1: I mean, personally for me it came from more understanding myself more and understanding like stuff I've gone through my for myself and seen how it's affected my behaviour and life and it makes it a lot easier than to look at someone else and go ohh well maybe (laughs)

Sydney, Katie
Becoming more aware of trauma through experience

Sydney, Katie
Trauma affects how people behave

Sydney, Katie
Link between past and present is obscured

Sydney, Katie
Meaning of behaviour is lost

Sydney, Katie
Significance of trauma becoming more recognised

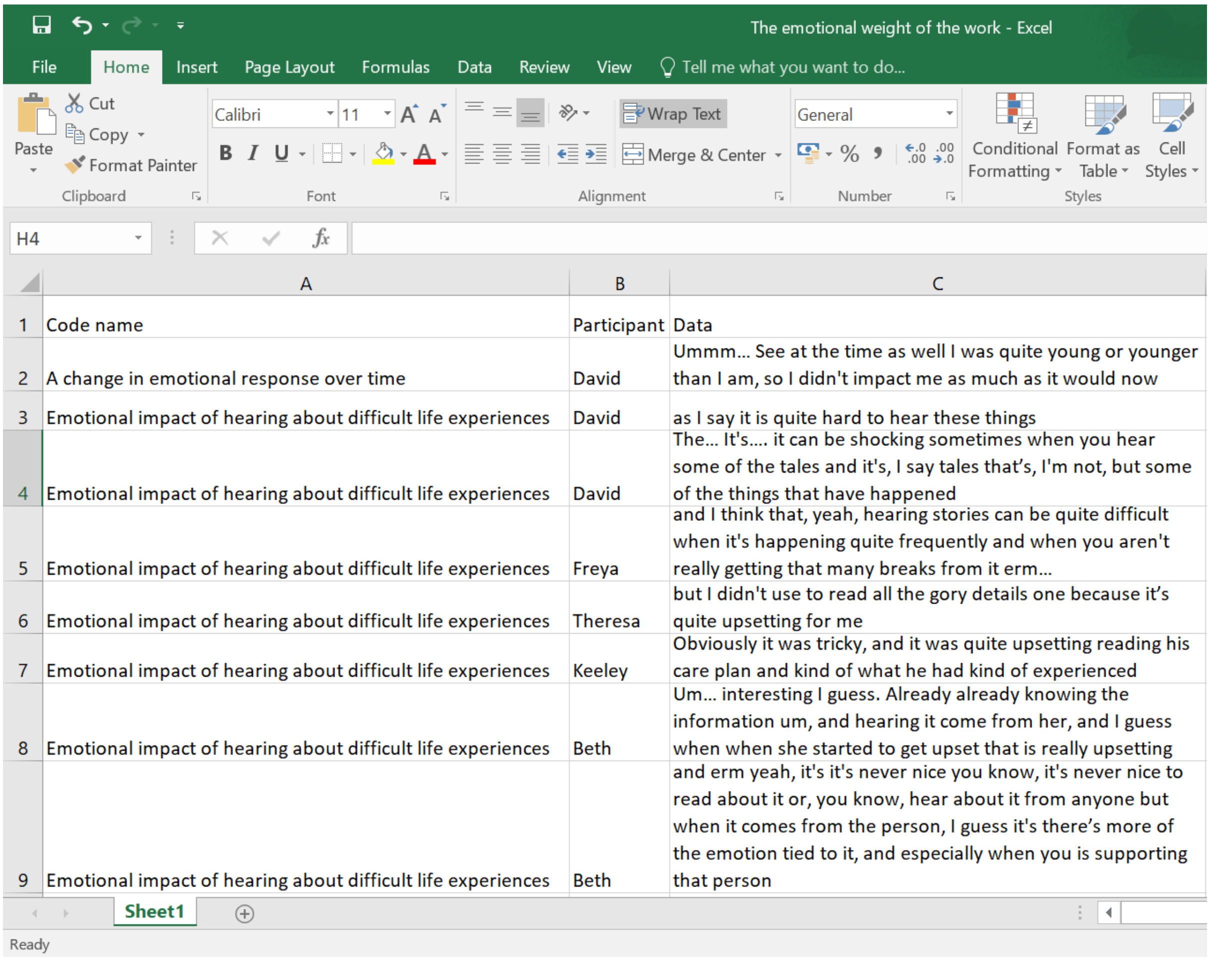
Sydney, Katie
Uncertainty about how to understand people

Sydney, Katie
Staff re-enacting trauma

Sydney, Katie
Conditions in care may put staff off

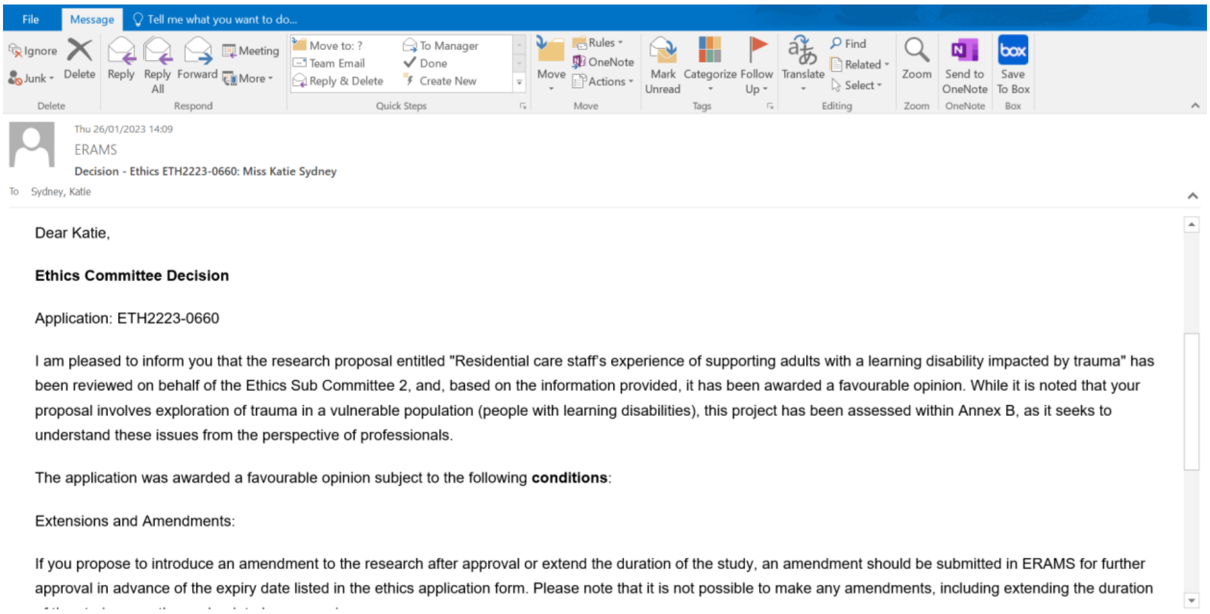
Sydney, Katie
Relating on a human level

Appendix G – Example collation of codes and coded extracts of data



	A	B	C
1	Code name	Participant	Data
2	A change in emotional response over time	David	Ummm... See at the time as well I was quite young or younger than I am, so I didn't impact me as much as it would now
3	Emotional impact of hearing about difficult life experiences	David	as I say it is quite hard to hear these things
4	Emotional impact of hearing about difficult life experiences	David	The... It's.... it can be shocking sometimes when you hear some of the tales and it's, I say tales that's, I'm not, but some of the things that have happened
5	Emotional impact of hearing about difficult life experiences	Freya	and I think that, yeah, hearing stories can be quite difficult when it's happening quite frequently and when you aren't really getting that many breaks from it erm...
6	Emotional impact of hearing about difficult life experiences	Theresa	but I didn't use to read all the gory details one because it's quite upsetting for me
7	Emotional impact of hearing about difficult life experiences	Keeley	Obviously it was tricky, and it was quite upsetting reading his care plan and kind of what he had kind of experienced
8	Emotional impact of hearing about difficult life experiences	Beth	Um... interesting I guess. Already already knowing the information um, and hearing it come from her, and I guess when when she started to get upset that is really upsetting
9	Emotional impact of hearing about difficult life experiences	Beth	and erm yeah, it's it's never nice you know, it's never nice to read about it or, you know, hear about it from anyone but when it comes from the person, I guess it's there's more of the emotion tied to it, and especially when you is supporting that person

Appendix H – Confirmation of ethical approval



Thu 26/01/2023 14:09

ERAMS

Decision - Ethics ETH2223-0660: Miss Katie Sydney

To Sydney, Katie

Dear Katie,

Ethics Committee Decision

Application: ETH2223-0660

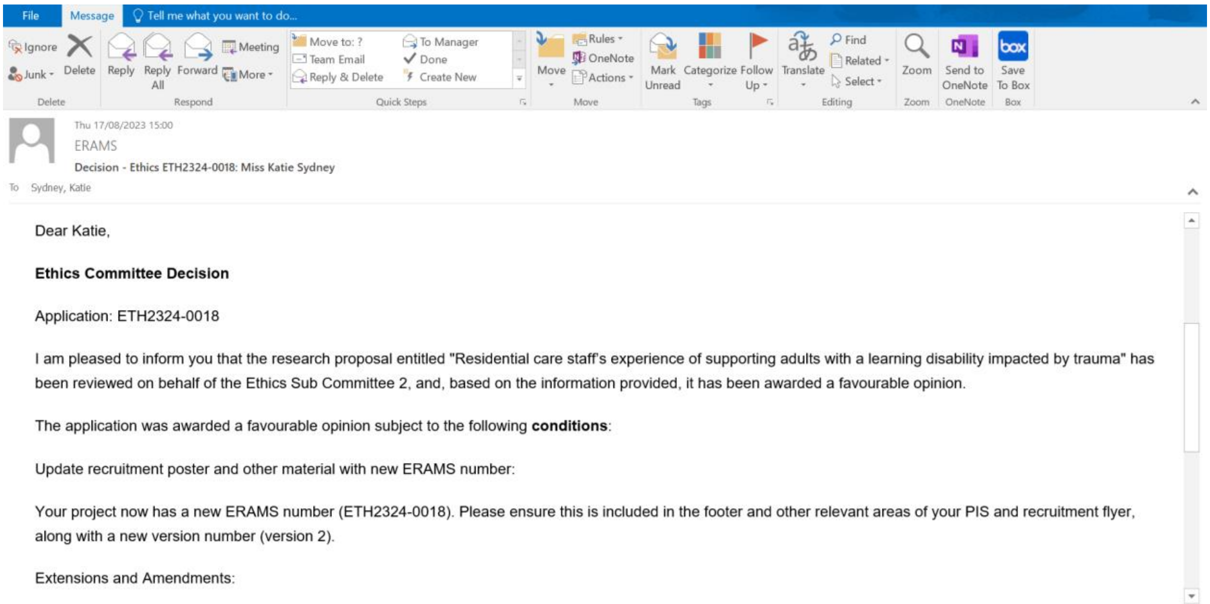
I am pleased to inform you that the research proposal entitled "Residential care staff's experience of supporting adults with a learning disability impacted by trauma" has been reviewed on behalf of the Ethics Sub Committee 2, and, based on the information provided, it has been awarded a favourable opinion. While it is noted that your proposal involves exploration of trauma in a vulnerable population (people with learning disabilities), this project has been assessed within Annex B, as it seeks to understand these issues from the perspective of professionals.

The application was awarded a favourable opinion subject to the following **conditions**:

Extensions and Amendments:

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in ERAMS for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration

Appendix I – Confirmation of ethical approval following study amendments



Thu 17/08/2023 15:00

ERAMS

Decision - Ethics ETH2324-0018: Miss Katie Sydney

To Sydney, Katie

Dear Katie,

Ethics Committee Decision

Application: ETH2324-0018

I am pleased to inform you that the research proposal entitled "Residential care staff's experience of supporting adults with a learning disability impacted by trauma" has been reviewed on behalf of the Ethics Sub Committee 2, and, based on the information provided, it has been awarded a favourable opinion.

The application was awarded a favourable opinion subject to the following **conditions**:

Update recruitment poster and other material with new ERAMS number:

Your project now has a new ERAMS number (ETH2324-0018). Please ensure this is included in the footer and other relevant areas of your PIS and recruitment flyer, along with a new version number (version 2).

Extensions and Amendments: