Katie Nic Dhonnacha BA Hons HDip MSc

SURVIVORS OF TRAUMA: EXPLORING STAFF EXPERIENCES WORKING IN INTELLECTUAL DISABILITY SETTINGS

Section A: Exploring experiences of staff working in complex intellectual disability settings: A review of the literature Word Count:8623 (623)

Section B:

Exploring staff experiences of psychodynamic trauma-informed care in complex intellectual disability settings. Word Count: 8499 (500)

Overall Word Count

17,122

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Clinical Psychology

November 2024

SALOMONS INSTITUTE CANTERBURY CHRIST CHURCH UNIVERSITY For Gearóid

Acknowledgements

The completion of this research has been realised through a million tiny acts of kindness, and many large ones too.

I am indebted to the profound kindness, wisdom and patience of Emma Rye and Sue Holttum.

I am deeply grateful to the participants for their inspiring passion and courage.

To my mom and dad, for their unwavering love and belief in me every step of the way.

To Babú for offering me sanctuary, comfort and love nuair a tháinig an crú ar an táirne.

To my friends and family who supported and uplifted me along the journey.

And finally, Gearóid and Robin. I am where I am because of your love, support and sacrifices. Thank you.

Le buíochas agus gean.

Summary of Major Research Project

Section A

A systematic literature review was conducted to explore the experiences of staff who work with people who have an intellectual disability and may have diagnosis of personality disorder. Eight articles were identified. A thematic synthesis was conducted from which seven themes were identified: 'Nobody liked her'; 'An involved kind of role'; 'They tie you up in knots'; Controlled and uncontained; 'We just didn't have a clue'; Marginalised; 'You don't seem to move forwards'. High levels of distress and trauma were present in the data. Clinical and research implications are considered to safeguard staff wellbeing and quality of care.

Section B

Trauma and complex attachment styles are more prevalent in people with intellectual disability, however, this is often not well understood in care settings. The field of Trauma Informed Care (TIC) is growing in this setting. This study sought to explore staff's experience of psychodynamic TIC in relation to their work with clients with histories of trauma. Eight participants were interviewed having completed this training, and an interpretative phenomenological analysis was conducted which yielded four superordinate themes: 'Enlightened is Empowered', 'Emotional Impact of Learning', 'Moving the Wheels of Transforming Care' and 'Distress in the Role'. Research and clinical implications are considered.

Section A	
Abstract	
Introduction	
Definitions and critique of diagnostic terms	
Trauma in the context of intellectual disability	
The current review	
Research Question	
Method	
Search strategy	
Eligibility criteria	
Metasynthesis	
Review	
Quality Assessment	
Quality of Literature	
Synthesis of the literature	
'An involved kind of role'	
'They tie you up in knots'	
Controlled and uncontained	
'We just didn't have a clue'	
Marginalised	
You don't seem to move forwards'	
Discussion	
'An involved kind of role'	
'They tie you up in knots'	55
Controlled and uncontained	
'We just didn't have a clue'	
Marginalised	
'You don't seem to move forwards'	
Clinical Implications:	
Research Implications	61
Limitations	

Table of Contents

Conclusion	62
References	63
Section B	75
Abstract	76
Introduction	77
Trauma Informed Care (TIC)	78
Rationale for attachment and psychodynamic principles in TIC	80
Caring for a Person with Personality Disorder and Intellectual Disability Training (CaPDI	D)82
The Present Research	82
Rationale	83
Aims:	83
Methodology	83
Design	83
Expert by Experience Involvement	84
Recruitment	84
Participants	84
Procedure	86
Analysis	87
Quality Assurance	87
Ethical Considerations	88
Results	89
1) Enlightened is empowered	89
2) Emotional impact of learning	93
3) Moving the Wheels of Transforming Care	96
4) Distress in the role	98
Discussion	101
Key findings	102
The outlier	105
Limitations	105
Clinical Implications	106
Research Implications	107
Conclusion:	107
References	108

Appendices	
Appendix A: Data extraction form	
Appendix B: Example of Thematic Coding: Descriptive Themes	
Appendix C: Thematic Synthesis: Example of Analytical Themes:	
Appendix D: Detailed Quality Review:	
Appendix E: Interview Schedule	
Appendix F: Consent form	
Appendix D: Information Sheet	
Appendix G: Reflexive Diary	
Appendix I: Ethical Approval	

List of Tables and Figures

Part A	
Figure 1: Prisma flowchart outlining systematic search	19
Table 1: Diagnostic Differentiators of BPD and cPTSD	14
Table 2: Inclusion and Exclusion Criteria of Current Review	21
Table 3: Summary of study characteristics	24
Table 4: CASP Summary	35
Table 5: Themes Identified in the Studies	38

Part B

ble 1: Demographic Data86

Section A

Exploring experiences of staff working in complex intellectual disability settings: A review of the literature

Candidate number: CP 4817285/19

Word Count: 8000 (623)

Abstract

Background: The experiences of staff working in settings of care for people with intellectual disability and trauma-related difficulties, such as personality disorder or complex post-traumatic stress disorder are not well represented in the literature. The clinical population can be complex to care for in terms of emotional and behavioural dysregulation and high risk, which can expose staff to stressful events. Despite the complexities and demands of the role, little is known in the literature about the experiences and needs of this group. A systematic review of the literature was conducted to shed light on staff experiences working in this complex field.

Method: A systematic literature review was conducted of three databases. Eight articles were included in the review, all of which employed qualitative methods, with one using quantitative elements also. The studies were assessed using quality appraisal tools and findings analysed using thematic synthesis.

Results: The overall quality of literature was strong. Seven themes emerged from the analysis, which were: 1) 'Nobody liked her'; 2) 'An involved kind of role'; 3) 'They tie you up in knots'; 4) Controlled and uncontained; 5) 'We just didn't have a clue'; 6) Marginalised; and 7) 'You don't seem to move forwards'.

Discussion: Staff in this area appeared to be traumatised. High levels of distress and cynicism were evident, in addition to reports of working environments that were not conducive to occupational wellbeing or high-quality care. Implications for clinical practice and research are discussed.

11

Introduction

The diagnosis of Personality Disorder (PD) is one that has been fraught with clinical, ethical and methodological controversies (Torr, 2003; Tyrer et al., 1991) as the label can carry pejorative and iatrogenic consequences of for those who bear it (Aviram et al., 2006). This becomes more contentious still when applied to people with intellectual disabilities (ID) for a variety of reasons. Traumatised people with ID can carry with them a confluence of vulnerabilities and complex needs that people in positions of care can struggle to meet or understand (Frankish, 2013). The people who have the power to name the individual as challenging or disordered are the people who do not have a learning disability, which speaks to an important power differential (Nunkoosing & Haydon-Laurelut, 2012; Pilgrim, 2001). Moreover, what is perceived as challenging can be determined by needs of the people labelling, rather than the individual in need of care (Emerson & Einfield, 2011). That being said, a diagnosis can be helpful if it facilitates understanding and appropriate treatment, though this can be complex with or without a 'PD' label.

Definitions and critique of diagnostic terms

The World Health Organisation (WHO, 2022) defines personality disorder as pervasive maladaptive cognitive, emotional, and behavioural patterns, which manifest across a range of personal and social situations, cannot be attributed to social or cultural factors, and which are associated with significant distress or impairment. The 'Borderline' PD descriptor is indicated for those who experience significant instability in relationships, identity and emotions, in addition to marked impulsivity. Acute sensitivity to real or perceived abandonment, self-harm, dissociative episodes, feelings of emptiness and difficulty managing anger are also hallmarks of this personality pattern.

The WHO (2022) defines complex post-traumatic stress disorder (cPTSD) as a pattern of severe and persistent difficulties with emotional regulation and maintaining relationships or experiencing intimacy, which occur in relation to prolonged and/or repetitive trauma. Diagnostic criteria of post-traumatic stress disorder must also be met, whereby an acutely traumatic event has occurred, one intrusively re-experiences this event and employs avoidance strategies to minimise triggers to distress related to this reexperiencing. One's perception of threat is altered such that it is persistently heightened. These symptoms are of a significant duration and severity, such that one's quality of life is significantly diminished.

BPD and cPTSD are distinct diagnostic categories, primarily distinguished in the ICD-11 as being a disorder of distress (cPTSD) or a disorder of the personality (BPD) (Hyland et al., 2019), however, there are areas of overlap among the diagnoses, namely difficulties in emotional regulation, self-concept, and interpersonal relationships. There are important differences too, which are outlined in detail in Table 1. Investigations into the validity of the differential diagnoses consistently find that there are significant differences (Owczarek et al., 2023), however, the utility and validity of diagnostic criteria for PD or cPTSD remain vigorously debated and unresolved (Cloitre et al., 2014; Jowett et al, 2020). Although trauma is not a diagnostic necessity in BPD, associations between trauma and the development of BPD are strong and consistently identified in the literature (MacIntosh et al., 2015). Prevalence data vary, however, estimates suggest that between 40 - 80% of people diagnosed with BPD also meet criteria for or have cPTSD diagnoses, in addition to 30 - 70% of people with BPD meeting criteria for having PTSD diagnoses (Ford & Courtois, 2021; Hyland et al, 2018). Ford and Courtois (2021) have suggested that BPD and cPTSD are like cousins diagnostically, in that they are different expressions of a stress response, which may be helpful in attempting to pick apart

13

either/or in a complicated and imperfect diagnostic system. It is important to acknowledge the debate in this field, in addition to how imprecise and potentially unhelpful these labels can be. These studies were of adults without a learning disability; therefore, it is unclear how the nuances of this resonate in an ID population. Comparative literature related to this topic in ID populations is not available at present (Cook & Hole, 2021), therefore drawing conclusions to its relevance must be done with caution.

Table 1:

Associated Symptoms	BPD	cPTSD
Trauma		
Traumatic event prerequisite of diagnosis	No	Yes
Avoidance of trauma symptoms	No	Yes
Re-experiencing of traumatic event	No	Yes
Elevated sense of threat	No	Yes
Emotional Disturbance		
Emotional reactivity	No	Yes
Affective instability	Yes	No
Intense Anger	Yes	No
Impulsivity in two areas or more of life	Yes	No
Suicidal behaviours	Yes	No
Self-injury	Yes	No
Transient stress-induced paranoia or	Yes	No
dissociation		
Chronic feelings of emptiness	Yes	No
Sense of self		
Pervasive sense of worthlessness and/or defeat	No	Yes
Unstable self-identity	Yes	No

Diagnostic Differentiators of BPD and cPTSD

Relationships

Difficulty maintaining relationships / tolerating	No	Yes
intimacy		
Frantic efforts to avoid abandonment	Yes	No
Unstable and intense relationships	Yes	No

Trauma in the context of intellectual disability

People with ID are much more likely than those without to experience traumatic events and abuses of any nature across the lifespan (McNally et al., 2021; Nixon et al., 2017; Schepens et al., 2019; Spencer et al., 2005). Social stressors such as rejection and discrimination are more common (Green et al., 2005), as are environmental stressors, such as poverty and unstable housing (Wigham & Emerson, 2015). Skelly (2020), posits that trauma may be more difficult for a person with an ID to process and recover from, due to greater difficulties in describing their experiences, identifying and understanding the emotional impact of it, and diminished agency to respond to the trauma. The high prevalence of trauma, in addition to the concomitant challenges associated with developmental delays, such as difficulties with communication and comprehension, leave a person with ID more susceptible to developing a presentation that could be labelled as PD (Pridding & Proctor, 2008). Prevalence data of PD diagnoses in ID populations are unreliable and highly variable, with community estimates ranging from 30 – 90% (Alexander & Cooray, 2002; Khan, 1997) and 40 – 90% in forensic populations (Alexander et al., 2012; Flynn et al., 2002).

Despite the estimated high prevalence of trauma and PD in this population, there are many challenges involved in identifying and diagnosing PD or cPTSD in a person with ID. It is widely accepted that PD is not an acceptable diagnosis for people with profound ID, but debate persists for people with mild or moderate ID (Gentile et al., 2022). This is in part due to a lack of clarity or consensus in the conceptualisation of disordered personality traits in people with ID (Andersen, 2015; Cooray et al., 2022; Emerson & Baines, 2010) and debate as to its utility or appropriateness (Lindsay et at., 2007; Naik et al., 2002). Furthermore, the term PD can have significant negative connotations; it can be used euphemistically and unhelpfully to describe an intractable personality, as opposed to a survivor of trauma (Rye et al., 2021). This may speak to an instrument of depersonalisation and denial to protect the person and organisation from anxiety related to caring for traumatised individuals (Halton, 1994; Menzies Lyth, 1988). Furthermore, this effect can be exacerbated by the absence of an adequate or safe organisational container, which is to say an unstable, unsafe or unsupportive work environment (Bion, 1961). Despite the aforementioned challenges and limitations of diagnostic labels in this area, having an appropriate diagnosis of complex trauma or personality difficulties may have clinical utility as it can guide appropriate understanding, care and treatment.

Terminology in the context of ID and PD

Terminology within ID and PD fields have been problematic and in a state of flux respectively for some time. The move away from dehumanising and pejorative labels is an important one (Johnstone & Boyle, 2018), however, the fluidity of the terminology has posed challenges, particularly when attempting to collate an evidence base. A glance at the search terms employed in the systematic search will outline how many names this population can go by, some more troubling than others. Huet (2011) presents the process of rebranding a group of people as a wider expression of society's impulse to look away from people with ID, a continuity of what happened in the institutions happening in microcosm with every new iteration. Sinason (1992, p. 39) described this process as a societal psychological defence, stating '*Euphemism, linguistically*, are words brought in to replace the verbal bedlinen when a particular word feels too raw or too near a disturbing experience'. The confluence of linguistic indecision in both realms of ID and PD has led to a blurry and amorphous evidence base which we struggle to name clearly, to see clearly, or to think about clearly (Sinason, 1989). The double vulnerability that comes with ID and PD brings with it a weight of responsibility for services to work reflectively and responsibly, however, the needs or experiences of professionals who deliver care to this complex group are not well considered or understood in the literature. They are themselves, by extension, unseen and poorly understood.

The author has a preference for the term intellectual disability as it is the most widely used in contemporary empirical discourse. For the purposes of this review the concepts of trauma and PD will be used flexibly in congruence with the position of the speakers/authors referenced.

The current review

The aim of the current review is to collate and synthesise the existing data on the experiences of people working with people who have an ID and PD/cPTSD. To date, no such review exists, which may be accounted for somewhat by the aforementioned challenges posed by heterogenous terminology across ID and PD milieu, in addition to a historic (and to a lesser extent, current) empirical indifference to this doubly marginalised group. An examination of this area could help to identify the needs of this group, in addition to guiding endeavours to shape trauma informed care and training. Ultimately, it is hoped that this review would shed light on how to deliver the best possible care to a vulnerable and overlooked population.

Research Question

What does the literature tell us about staff experiences of working with people with ID and trauma-related relational difficulties, such as PD or cPTSD? How can this guide advances in practice?

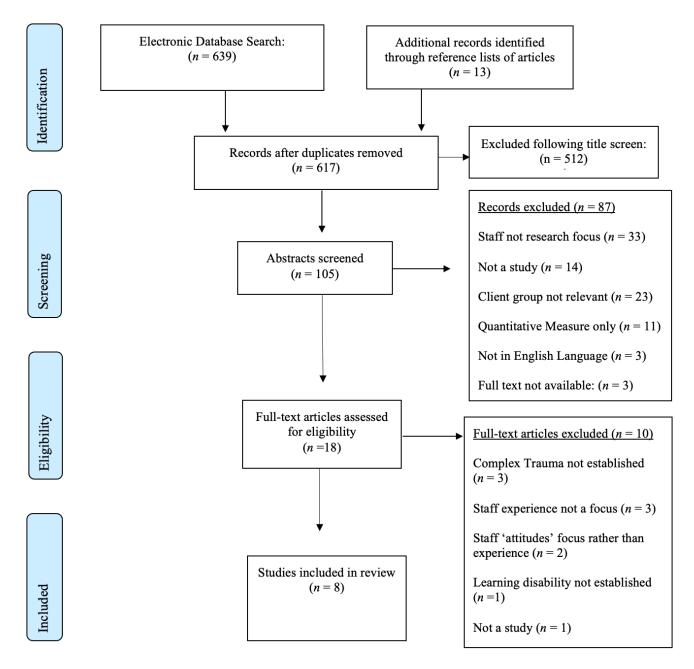
Method

Search strategy

An electronic literature search was conducted on the 19th June 2024 of PsychInfo, Web of Science, Medline/Pubmed and Proquest databases. Supplementary searches of Google Scholar were also conducted. The search terms and Boolean operators utilised were as follows: (("personality disorder*" or "PD" or "EUPD" or "complex needs" or "BPD" or "Borderline Personality Disorder*" or "Antisocial" or "Complex Trauma" or "CPTSD" or "relational trauma" or "attachment trauma") AND ("learning disab*" or "special needs" or "LD" or "intellectual disab*" or "ID" or "mental* retard*" or "global delay*" or "mental* handicap*" or "developmental* delay*" or "learning impair*" or "IDD") AND ("behav* that challenge*" or "challeng* behav*" or "behav* of distress") AND ("Staff" or "care team" or "direct car*" or "direct support staff" or "DSS" or "direct care work*" or "DCW" or "staff perspective*" or "Clinic*" or "vicarious trauma" or "secondary trauma" or "compassion fatigue")).

Figure 1:

PRISMA flowchart (Page et al., 2021) outlining systematic search.



Eligibility criteria

Inclusion and exclusion criteria were developed and applied to studies identified in the database searches, which are outlined in Table 2.

The scope of the review was deliberately broad and inclusive. This was considered appropriate considering to the paucity of literature in the area. Titles and abstracts were perused and selected in accord with relevance to the research question. The reference sections of relevant papers were systematically checked to identify other appropriate papers. Additionally, papers referencing the relevant papers were also checked. The process and studies produced by this search are outlined in Figure 1. The titles identified were: (1) Coates and Jones, (2020); (2) Dalgarno and Riordan, (2014); (3) Hudson, House, Robson, and Rayner-Smith, (2021); (4) Huet, 2011; (5) Lee and Kiemle, (2015); (6) Storey, Collis and Clegg, (2012); (7) Taylor and Trout, (2013); and (8) Zarotti, Hudson, Human, Muratori and Fischer, (2022).

Forensic studies were included in the search and examined for relevance to the research question, even in the absence of explicit references to PD or cPTSD. This was deemed appropriate due to prevalence of trauma and PD in this population. Studies were considered appropriate if hallmarks of PD were referred to, particularly in relational contexts, and excluded on the basis of no relevant emphasis on PD within the text. For example, some of the forensic papers examined offence or risk specific attitudes and experiences, did not address the research question, and thus were excluded from the review.

Table 2:

Inclusion and Exclusion Criteria of Current Review

Category	Inclusion criteria	Exclusion criteria
Research focus	The experiences of staff working with in the domain of care provision for people with learning difficulties and complex trauma is examined.	Staff members' experience of their work/field is not a focus of the research.
PopulationCare staff working with people with intellectual disability and complex relational trauma, such as personality disorder or complex post-traumatic stress disorder.		Study does not pertain to staff working with people with intellectual disability and relational trauma such as personality disorder or post- traumatic stress disorder.
Setting	Care settings, either inpatient or community. General and forensic settings. Public and private care provision. Service supports people with learning disability and complex trauma.	Care provision not primary function of setting. Setting not related to learning disability or complex trauma care provision.
Study type	Qualitative studies, mixed methods designs	Quantitative studies without qualitative aspect
Language English		Non-English
Publication	Published studies, grey literature, doctoral research, unpublished studies.	None
Time frame	Any time frame eligible.	None

Metasynthesis

The review was conducted according to procedures of thematic synthesis outlined by Thomas & Harden (2008), in which the findings from multiple qualitative studies were synthesised and amalgamated into data from which new perspectives pertaining to the research question were

examined. This analysis was selected due to dual function it served in terms of summarising qualitative data and generating novel perspectives and interpretations (Finfgeld-Connett, 2010).

Primary source data were extracted verbatim from studies. An inductive approach was used, meaning the codes were determined by the data rather than by pre-existing theoretical frameworks. The text was coded line-by-line from which initial descriptive codes were generated, which adhered closely to the manifest data and allowed for translation of concepts between studies, following from which, analytical themes were developed.

Review

The studies included in the review are described collectively, key features of which, such as the design, methodology, populations and results are summarised in Table 3. A data extraction form was used to collate relevant information from the respective studies (see Appendix A). Eight studies in total were included in the review, seven of which were qualitative and one (Taylor & Trout, 2013), employed a mixed methods design. All studies were conducted in the UK apart from Coates and Jones (2020), which took place in Australia.

Participants:

The sample consisted of 72 people. Females comprised 47% of the sample (n = 34), 32% of the sample were male (n = 23) and the remaining 21% is unknown (n = 15). The only data in terms of nationality or ethnicity was provided by Lee and Kiemle (2015), for which all nine participants were White British. Age ranges were given for two studies, (Huet, 2011; Storey et al., 2012), which were 35 - 48 years (mean 42) and 'early twenties to late fifties' respectively.

The named majority of the participants were nurses by profession, making up 42% of the population (n = 31), though this is likely an underestimation, as Taylor and Trout (2013) alluded to its population as a 'nursing team' which may have comprised of a mixture of qualified nurses,

students or healthcare assistants. The remainder of the population were a mixture of managers, psychologists, speech and language therapists, psychiatrists, social workers, occupational therapists, and behavioural specialists.

Table 3

Summary of Study Characteristics

Study (year), location of study	Aims/focus of research	Inclusion criteria	Sample	Design and Analysis	Summarised findings, themes and subthemes
1.Coates & Jones (2019) Australia	To shed light on experiences of mental health practitioners in managing the needs of people with LD and offending histories. To explore how the needs of the people with LD and offending histories can better be met.	Client-facing employees of a government commissioned organisation supporting forensic clients in the community.	14 healthcare professionals 8 males, 6 females across residential and community settings in rural and metropolitan areas. Sample made up of managers (n = 3) and clinical staff (n =11) which were a mix of social workers, psychologists , behavioural specialists and support workers.	Semi-structured group interviews. 4 groups in total with between 2 and 7 participants. Thematic Analysis combining inductive and deductive methods.	 Staff well-being: Raised by all participants, the importance of support for their own mental health was central to doing and sustaining their role. Peer and organisational support was considered vital. Client complexity in terms of managing and prioritising multiple competing needs for the person, organisation and public. Victimisation: This was considered in terms of discrete traumatic experiences and compounding layers of social disadvantage due to LD and offending. Poor comprehension: Participants described that clients struggled greatly to comprehend the legal structures that they were bound by, which increased the importance of their role as educator and advocate. Institutionalisation: Concerns regarding loss of functional skills and independence following a period of incarceration, which was compounded for people with learning disability considering the social disadvantages they face. Poor responses from external services: Mental Health: Mental health presentations were assumed to be 'behavioural' and therefore viewed in context of the person's LD rather than their mental health needs. Police: Police were seen as inconsistent and inappropriate responses, sometimes not responding to acute risk and at times being disproportionately heavy handed. Multiagency working Referrals were often perceived to be rejected on unreasonable grounds with poor multiagency collaboration. Slow-moving bureaucratic processes compounded by many organisations involved mean that progression is

Study (year), location of study	Aims/focus of research	Inclusion criteria	Sample	Design and Analysis	Summarised findings, themes and subthemes
					frustratingly slow which is painful to see in terms of impact on the client.
					Responses to risk Ethical concerns for participants in terms of the competing and opposing frameworks of disability and forensic approaches.
					Funding Changes to the social benefits system, similar to that of 'universal credit' in the UK, creating chaos and instability.
2. Dalgarno & Riordan (2014) UK	To qualitatively examine the lived experiences of learning disability nurses working within forensic services, and their views on their practice as a specialty.	Qualified nurses in a forensic learning disability service.	4 nurses working in the same NHS trust. All had ten or more years of experience in	Semi structured individual interviews Interpretative Phenomenological Analysis	It is the same and it is different. Characteristic and skills required in role were perceived universal in LD nursing, such as being more 'involved' and adaptive with clients. Forensic population being perceived as more 'able' cognitively than non-forensic LD community, which was perceived as adding to complexity and challenges involved in the role.
	praetiee as a specially.		their roles. Gender and age information was omitted to protect anonymity of the participants.		It is an emotional challenge. <u>Generally:</u> Participants spoke to the difficulties coping with the forensic histories of the service users they were caring for and broader challenges of the professional setting were also prominent, such as the uncertainty surrounding what success in care looked like in such a challenging and complex care environment. <u>Failure:</u> A prominent emotional challenge was described as the sense of failure staff felt when a client was stepped up in terms of security or behaved violently.
					It is a journey. Participant expressed a change of outlook and emphasis in terms a move toward client-centred care and holding an empowering stance.

Study (year), location of study	Aims/focus of research	Inclusion criteria	Sample	Design and Analysis	Summarised findings, themes and <u>subthemes</u>
					It is a balancing act: Managing the tension between the client's needs and the public protection in terms of positive risk taking was a prominent feature of the nurses' experience.
					Language matters: Participants expressed that the label of 'forensic' had an impact on their sense of their role as different to non- forensic roles, above and beyond the differences they actually perceived in terms of risk or challenges.
3. Hudson et al., (2021)	To qualitatively explore and compare	Qualified RNLD working within	9 RNLD Community	Semi structured individual interviews	<u>Convergent Themes:</u> Impact on discharges:
UK	the experiences of inpatient and community based forensic LD nursing staff working during 'Transforming Care' (TC) programme of deinstitutionalisation.	inpatient or community forensic intellectual disability services. Employed as RNLD since 2015 when roll out of TC started. Working in client- facing role.	sample (<i>n</i> = 5) Inpatient sample (<i>n</i> = 4) 4 males and 5 females	Multi-perspectival Interpretative Phenomenological Analysis	 <u>Rushed discharges:</u> Pressure to rush or expedite discharges to the community that staff felt clients were not ready for. Targets and deadlines for discharges were not sensitive to client needs or flexible to clinical judgment. This resulted in fear, frustration and anxiety that harm would befall the client or a member of the public, which nurses felt responsible for. Representatives of TC were perceived as removed and naïve to the realities of forensic LD services and protected from the consequences of premature discharges. <u>Delayed discharges:</u> TC perceived as permeated by bureaucratic systems and processes in which links in the discharge chain between services would remain in stasis for months at a time. Associated feelings of frustration. Community infrastructure inadequate or unequipped to meet needs of forensic clients. Frustration at the feelings of 'stuckness'. Resistance to discharge on the part of the client as a result of instituionalisation.

Study (year), location of study	Aims/focus of research	Inclusion criteria	Sample	Design and Analysis	Summarised findings, themes and subthemes
					Divergent themes: Riding the wave of TC Community staff embracing the change presented by TC, approaching opportunities with renewed sense of creativity. Tangible benefits identified by community sample who expressed TC had improved or created links with community agencies and resources. A change of identity within role to a less siloed position to one in which influence of expertise can shape care packages and appropriate placements.
					Crushed by the wave of TC TC experienced as watchful and intimidating. TC experienced as separate to the reality of forensic nursing, which participants believed would largely remain the same despite TC. Frustration expressed at the circularity of deinstitutionalisation.
4. Huet (2011) UK	To explore the experiences of people working with people with learning disability in a secure setting.	Participants were client-facing staff from a secure ward for people with LD.	N = 2 Both were female. One support worker Other participant's occupation was not disclosed.	Thematic analysis of verbal content and psychodynamic interpretation of the artworks.	Alienation: A sense that clients are sequestered out of sight from the public who do not want to see or acknowledge them. This leaves the staff members with a sense of being unseen also, as people around them do not relate to their experiences or do not want to know. A sense of alienation between staff members and their clients due to the profound gulf between their lived experiences and needs. A longing for closeness from the part of the clients that the staff cannot fulfil.
					Control vs Containment: The tension between being a secure environment and a therapeutic resource. Painful dissonance that arises from restraining a person physically having built a therapeutic relationship with them. A sense of inner constraint arising as a result of suppressing angry reactions to being shouted at or abused. This also

Study (year), location of study	Aims/focus of research	Inclusion criteria	Sample	Design and Analysis	Summarised findings, themes and subthemes
					related to having to implement care plans that they might not agree with that were decided by consultants who were relatively removed from the pragmatics of care. Giving an outward appearance of control in spite of fear related to sudden outburst of violence. This pretence of control was perceived to the mechanism that stopped a bad situation escalating to a catastrophic situation.
					 Working with Fear: Exuding calm and professionalism despite anxiety regarding constant threat of violence. 'Putting on a good show' of calmness and sympathy essential to appearance of competence to clients and other staff members. 'Macho' manifest behaviour at odds with feelings of vulnerability, leaving staff members feeling 'fake'.
					Power and powerlessness: The client's learning disability is a defining influence of their distress and risk, and this state of being cannot be changed. Decision making power comes from the top down and from considerable distance. The job of implementing, translating and mediating these decisions whilst not having a voice in making them compounded feelings of powerlessness.
5. Lee and Kiemle (2015) UK	To qualitatively examine the experiences of nurses working with people with LD and PD in a medium-secure forensic intellectual disability setting.	Qualified nurses working with people with diagnoses of LD and PD in inpatient forensic services,	N = 9 2 male, 7 female Ages 35 – 48 (mean 42) Post- qualification 14 months - 24 years (mean 9.3 years)	Semi structured individual interviews IPA	Disorder overriding disability: Distinct lack of dialogue considering LD despite interview schedule giving equal importance to LD and PD. <u>Negative traits attributed to PD</u> Clients described as 'manipulative', 'self-centred' and 'lacking in empathy'. <u>Relationally difficult</u> Difficulty forming a meaningful therapeutic relationship due to strategies employed by staff to remain distant to manage or counteract 'manipulation'. <u>A need for structure</u>

Study (year), location of study	Aims/focus of research	Inclusion criteria	Sample	Design and Analysis	Summarised findings, themes and <u>subthemes</u>
			5 staff nurses 2 ward managers 2 advanced practitioners. All participants were white British.		Participants expressed that due to PD the environment could feel overwhelming and chaotic, therefore structure and boundaries were essential. Some participants felt as though protecting and upholding structure and boundaries was a constant task as clients with PD were bent on unravelling this. <u>Challenges attributed to PD</u> The challenging nature of the role were nearly entirely attributed to PD sense that the work was draining, relentless, futile and frustrating. Team splitting was referred to as being emotionally challenging in that staff felt 'blamed' from both sides of split. Resilience Persevering despite challenges and protecting oneself from burnout was a prominent theme. <u>Focus on the positives:</u> The clients support one another well and can show compassion when one is struggling. The participants described a self-assuredness, sometimes a performance of confidence that was deemed necessary to 'keep control' and signal their authority. <u>Remaining emotionally distant</u> A unanimous theme, deemed essential to remaining rational in an emotionally charged environment, such as when tending to self-injury. There was an acknowledgment that this may leave clients' underlying need untended to. Ambivalence toward label <u>Victim or perpetrator?</u> Complex differences arising according to gender of client. Males perceived as abusers and females as victims who are trickier to care for due to self-injury and bearing grudges. Equal split in participant' placement of responsibility on client for their behaviour (perpetrator) or on their PD and trauma (victim).
					29

Study (year), location of study	Aims/focus of research	Inclusion criteria	Sample	Design and Analysis	Summarised findings, themes and subthemes
					<u>A need to see the person behind the label</u> Understanding clients' distress and as an inevitable consequence of trauma enabled participants to see beyond PD label and hold empathy.
					KnowledgeImportance of knowledgeRaised by all participants as anessential component of care in PD. A small number ofparticipants struggled to describe or define PD. Knowledgeof theory and in-depth knowledge of the person given equalweight.Knowledge increasing over time:Understanding and knowledge increasing over timecommon narrative.Increased insight mitigating the chaos of the work andfeelings of frustration.Lack of training and a sense of frustration at having to 'get
6. Storey et al., (2012)	To explore the experiences of direct care staff working with	Purposive sampling from an inpatient ward	N = 8. 5 male, 3 female	Free association narrative interview. Psychodynamic	on with it' without adequate preparation. The participants' experience of themselves: Feeling as though they are lacking in training and necessary knowledge.
UK	care stall working with people with LD and BPD diagnosis. Secondary aim to explore if concept of countertransference is appropriate/ helpful in understanding staff experiences.	supporting people with LD/BPD.'Direct care staff'	6 qualified nurses and 2 nurses assistants. Age range: early twenties to late fifties.	interpretation of transcribed interviews guided by transferential and countertransferential experience of researcher. Individual interviews with open-ended questions related to work experience.	Feeling powerless to steer treatment or care of service users despite being mainstay of implementation of it Remaining positive and resisting pessimism <u>Researcher's interpretations:</u> Anxiety and uncertainty prominent in conversations. Intellectualisation prominent as a defence against feelings of uncertainty, a sense that more training would solve problem of uncertainty. Noted absence of negative feeling toward service users, related by researcher to lack of safety in the therapeutic relationship and fear of being judged.
					The participants' view of the organisation Insufficient and inconsistent staffing most stressful aspect of role. Over-reliance on bank staff leaving longstanding

Study (year), location of study	Aims/focus of research	Inclusion criteria	Sample	Design and Analysis	Summarised findings, themes and <u>subthemes</u>
					 members of staff feeling alone on shift as sole holders of expertise on clients. Substantive staff banned from doing overtime during cour of study. This added to feelings of powerlessness over shaping work environment and isolation, as staff members often did not know team members of shift. Client group very mixed in terms of age, gender, cognitive ability leading to feelings of inability to meet their varied needs. Feelings of powerlessness to influence accepted referrals to ward. <u>Researcher's interpretations:</u> Participants' feelings of powerlessness related to their lack of control in influencing referrals or staffing added to the difficulty of the role and feeling of distress and perceived complexity of their role. Denial prominent defence (Malan & Parker, 1995) in whice some participants outlined their powerful position as expendence in their from their intolerable distress at their lack of control.
					 Perception of clients: Difficult experiences related to physical or verbal abuse th felt targeted and personal in nature. Clients skilled at hurting or causing emotional impact. Experiencing emotional impact perceived as weakness by participants. <u>Researcher's interpretations:</u> Switch in emphasis to organisational dynamics being more troublesome and lasting in their effects than abuse from clients, at which point participants access feelings of frustration and powerlessness. Unacceptable negative feelings toward clients projected into organisation. Suppression of traumatic events posited as necessary for survival in role.

Study (year), location of study	Aims/focus of research	Inclusion criteria	Sample	Design and Analysis	Summarised findings, themes and <u>subthemes</u>
7. Taylor & Trout (2013) UK	To explore the staff experiences of working in a newly opened forensic therapeutic community for people with LD and PD.	Purposive sampling from therapeutic community.	Qualitative sample: $N =$ 11 Quantitative sample: $N =$ 17-19 Occupation not stated but 'nursing team' is implied suggesting nurses and nursing assistants. No other demographic data.	Qual: Focus groups Thematic analysis Quant Measure: The Essen Climate Evaluation Schema (Schalast et al., 2008) 17-item questionnaire assessing social and therapeutic climate of forensic psychiatric wards administered 4 weeks, 6 months and 18 months into ward opening.	NB Themes and subthemes were not described or given context. Multidisciplinary (MDT) Working Confusion re MDT Clarity re MDT working Management Support was described as a concern (lack thereof presumably though not made explicit). Nursing team/practice Team cohesion and stress Support of one another in the team referenced as a 'concern' without elaboration. Model bedding in: Concerns about balancing the need for security with the needs of therapy Diverse and multiple demands Increased openness and honesty Improved relationships with patients Understanding risk: Greater understanding and insight into risk Increased tolerance of more challenging and risk-related behaviour Aspirations Reflection/process time Clearer assessment and discharge pathways
					Clearer assessment and discharge pathways Staff training Communication with senior managers EssenCES results: Nurses sense of 'experienced safety' "similar to national norms" and increased slightly over 18 months. Whether or not they felt safe was unclear. 'Therapeutic Hold' measuring their dedication to the role decreased slightly over time.

Study (year), location of study	Aims/focus of research	Inclusion criteria	Sample	Design and Analysis	Summarised findings, themes and <u>subthemes</u>
8. Zarotti et al., (2022). UK	To explore the subjective experiences of healthcare professionals (HCP) working with people with diagnoses of LD and PD. To explore HCP's perception of utility of PD diagnosis.	Healthcare professionals working in client- facing roles with clients with combined diagnoses.	N = 15 7 Nurses 2 Clinical psychologists 1 Assistant psychologist 1 Support worker 1 Psychiatrist 1 Occupational Therapist I Ward manager 1 speech and language therapist	Thematic analysis Focus groups, 3 with 5 participants per group	 'It's knowing the person as well': Diagnostic issues and the need for person-centred approaches: Diversity of presentations, including issues around overlapping symptom and clients' difficulty engaging with assessment process: Person-centred approach: Focus on presentations and narratives rather than labels: Pros and cons of diagnosing: Balancing stigma of label vs treatment opportunities and better understanding. Traits vs. diagnosis: HCPs reported that traits/ adaptations associated with PD were commonplace and that formal diagnoses comparatively rarer. 'You've got to try to put up boundaries': Challenges and adjustments to working with people with combined LD and PD diagnoses: Communication and social difficulties: Comprehension and social skills leading to complexity in care provision and loneliness on part of client. Dependency and boundaries: Attachment seeking and intensity in relationships Increased risk and vulnerability felt in relation to clients safety and the HCPs safety. Management and discharge issues in relation to provision for complexity and ambivalence around discharge and loss of attachments. 'I think it's talking to your colleagues, isn't it?': the importance of MDT training, support, and cohesion: Lack of key staff who could offer support or leadership such as psychology and psychiatry. Lack of training and confidence working with clients presenting with PD traits/diagnoses within the context LD, particularly considering how challenging and mixed presentations can be.

Study (year), location of study	Aims/focus of research	Inclusion criteria	Sample	Design and Analysis	Summarised findings, themes and subthemes
					<u>Need for MDT cohesion:</u> Differences in opinion experienced as challenging and stressful.
					 'Unfortunately, a diagnosis also means a service': provision issues and barriers to service access: Significant issues with services' ability to provide appropriate care for people with both LD and PD as well as clients difficulty accessing it. Diagnostic overshadowing and gatekeeping: The LD label overshadowing PD and therefore referral to PD specialty service seen as highly unlikely. Importance of interservice liaison: Tribalism in relation to diagnoses and what services interpret as primary diagnosis (PD or LD) and lack of flexibility or cohesion. Low wages and resources: Low incentive to work in high risk, high stress and high responsibility role with low wage and low support. Need for guidance and supervision

Quality Assessment

The quality of studies was appraised using the CASP checklist, (Critical Appraisal Skills Programme, 2018), the results of which are outlined in Table 4. All studies were included in the review, irrespective of quality ratings due to the dearth of available literature. Quality ratings were considered when interpreting the findings. Please refer to Table 3 for legend of studies.

Table 4

CASP Summary

Criterion MetCannot TellCriterion unmet								
Study by number:	1.	2.	3.	4.	5.	6.	7.	8.
Q1. Clear aims?								
Q2. Qualitative Methods Appropriate?								
Q3. Design appropriate?								
Q4. Recruitment strategy appropriate?								
Q5. Data collection appropriate?								
Q6. Relationship between researcher/participants considered?								
Q7. Ethics considered?								
Q8. Data analysis rigorous?								
Q9. Clear statement of findings?								
Q10. Is research helpful or valuable?								

Quality of Literature

The overall standard of the body of literature was strong. All studies employed reasonable methodological designs to address their expressed aims. Most studies demonstrated sufficient transparency and clarity to reassure the reader that analyses were conducted with rigor and integrity. Coates and Jones (2019) and Hudson et al., (2021) were outstanding examples, and the only designs to employ response validation to participants prior to publication. Most studies approached ethical considerations of their research transparently and judiciously, though Zarotti and colleagues (2022), Huet (2011) and Lee and Keimle (2015) stood out in this regard. Storey et al., (2012) employed the least mainstream design in the form of a psychodynamic research method; they provided ample primary source materials, manifest and interpretative content were clearly demarcated, in addition to explicit quality procedures. Huet (2011), which also included psychodynamic interpretation as research methods did this to high standard also. Both these studies were notable for their ethical and caring approached to the participants and the clients they work with.

Huet (2011) paid the most attention to naming and addressing sources of bias, which they reported to the highest standard in the review. There was satisfactory attention paid to bias in broad strokes, however, author reflexivity was the most difficult standard to assess, with only Hudson et al., (2021), Huet (2011) and Storey et al., (2012) making observable references to this.

Dalgarno and Riordan (2014) only had four participants, which may not have been sufficient for adequate data saturation, which may be why their results were more descriptive and less interpretative than one would expect given the IPA methodology (Brocki & Wearden 2006). That said, the richest discussion and most considered interpretations of all the papers in the review were that of Huet (2011), which had the fewest participants (n = 2).

36

The poorest quality study was Taylor and Trout (2013), in which procedures and ethical considerations were not well outlined and reporting of the results of the thematic analysis was negligible. A total of two sentences of what participants shared made it to the final report, rendering the themes inaccessible to the point of meaningless, demonstrating an unethical treatment of qualitative data in relation to the expressed values and goals outlined by Braun and Clarke (2006).

All studies were sparing in their demographic descriptions of participant groups, the result of which is a weak understanding of the group as a whole. Coates and Jones (2020) outlined the level of educational attainment, Lee and Kiemle (2015) described the ethnicity of the participants and Dalgarno & Riordan (2014) and Storey et al., (2012) reported age ranges. Only Dalgarno and Riordan (2014) named the omission of demographic data as a deliberate manoeuvre to protect the confidentiality of the participants, who are vulnerable to identification due to the small and specialised nature of the work. It is likely that these factors influenced other studies also, although it was not made explicit elsewhere.

The value of the body of research as a whole was high. Scientific and ethical rigor were high across the board, which meant that all studies had something to offer this particularly neglected field in the literature. The only poor example in the review in terms of rigour and content still offered something valuable in terms of process and offered something novel to the body of literature.

Table 5

Themes Identified in the Studies

Themes Subthemes	Number of studies reporting	Studies	Example Quotation (source)
'Nobody liked her'	8	1, 2, 3, 4, 5, 6, 7, 8.	"In a nutshell, would you want them living next door to you?" (Hudson et al., 2021). "She was typical PD. Where, nobody liked her,erm, it's everybody else's fault. If she had done anything wrong, it was always somebody else's fault'. (Lee & Kiemle, 2015).
'the majority are compulsive liars': Problematic Personalities	6	2, 3, 4, 5, 6, 7.	"the majority of them are compulsive liars, [pause] and it sounds awful that doesn't it" (Lee & Kiemle, 2015). "they're not always the most likeable people". (Lee & Kiemle, 2015).
'She [] pushed my buttons': Complex Relationally	5	1, 3, 5, 6, 8,	"She'd also know things that pushed my buttons that was really tiring, 'cos she would just be on you and you knew, you'd trip up before she would if you weren't careful 'cos she was that good at itshe'd always manage to trip me up'. (Storey et al., 2012). "they'll try and manipulate, that's part of the personality disorder"(Lee & Kiemle, 2015). "we assumewe know someone's feelings, but what's happening on the outside is not really connected with what's happening on the inside' (Huet, 2011)
'Overshadowed': Complex Presentations	3	1, 2, 8.	"People who are more able present more challenges and present more obstacles to overcome before you get to know the person and get to the root cause of their [] behaviour". (Dalgarno & Riordan, 2014). "PDis almost overshadowed by the intellectual disability." (Storey et al., 2012).

Themes	Number of studies	Studies	Example Quotation (source)
Subthemes	reporting		
'Everyone had tragic lives':	2	1, 5.	"I haven't worked with a client that hasn't first been a victim." (Coates & Jones, 2019). "in my experience without fail, everyone had tragic lives really."((Lee & Kiemle, 2015).
'An involved kind of role'	7	1, 2, 3, 4, 5, 6, 8.	"you start off stabbing in the dark, and finding out more about specific offence related stuff, but you're looking at stuff that's mental health based [] and it's trying to use your learning disability knowledge to adapt." (Coates & Jones, 2019). "it's quite an involved kind of role I think. It's quite separate from other nursing roles" (Dalgarno & Riordan, 2014).
'There's lots of considerations'	5	1, 2, 3, 5, 8.	"My immediate thoughts are to make sure that they obviously that I get the, you know, the wounds cleaned up so there is no risk of infection Put the bandages on and all that but I think they are lacking the support emotionally." (Lee & Kiemle, 2015). "There's lots of considerations around risk to the public [and] risk to themselves" (Dalgarno & Riordan, 2014).
'Trying to support whilst restricting'	4	1, 2, 5, 8.	"It's an ongoing tension around how you balance risks and safety and that persons individual human rights." (Coates & Jones, 2019). "Trying to support a client to develop whilst restricting how they do those things" (Coates & Jones, 2019).
'They [] tie you up in knots'	7	1, 2, 3, 4, 5, 6, 8.	"Sometimes people with a personality disorder can tie you up in knots and can press your buttons." (Zarotti et al., 2022).

Themes Subthemes	Number of studies reporting	Studies	Example Quotation (source)
'it's quite frustrating'	7	1, 2, 3, 4, 5, 6, 8.	" it can be quite tiring cos obviously, a lot of the behaviours are repeated, over and over, And that's quite frustrating." (Lee & Kiemle, 2015). "[I] take it out on the motorists on the way home" (Storey et al., 2012).
'I am always looking over my shoulders'	7	1, 2, 3, 4, 5, 6, 8.	"I am always looking over my shoulders. Although I may be friendly and helpful, I am aware that at any point they could be trying to attack me or someone else." (Huet, 2011). "[staff] don't really want formal support, they don't like it, they're suspicious 'Why have you come to see me?' 'There's nothing wrong with me. (Storey et al., 2012). "it's alright other people saying well, we've done everything we can and we've got risk assessmentsyou still feel a lot of the pressure to protect the public" (Hudson et al., 2021)
'a boiling pot of chaos': Overwhelm	3	3, 5, 6.	 "It's like a rollercoaster ride, a boiling pot of chaos". (Lee & Kiemle, 2015). "Oh God, I can't remember, I think someone talked her down, I can't remember, I'd forgotten about it until someone mentioned it to me I thought 'God, I'd forgotten about that' you don't want to think about those times." (Storey et al., 2012). "switch off, you've got to be able to switch off you've got to be able to switch off you've got to log to switch off you've got al., 2012).
'I put on a good show': concealing emotion	3	4, 5, 6.	"The pressure is to appear 'confident that you will be able to react in the right way". (Huet, 2011). "Erm, being confident, certainly even when you're not feeling confident, it's coming across as confident". (Lee & Kiemle, 2015). "I feel I put on a good show [of calm] when I am at work", "It is quite an unsettling situation to be in. I feel a bit fake sometimes", (Huet, 2011).

Themes	Number of studies	Studies	Example Quotation (source)
Subthemes	reporting		
'How did I fail this person?'	2	2, 6.	"I think you feel a bit of a failure there's not always that amazing success, there is steps forward it does make you look at yourself and think, well what more could I have done here? How did I fail this person.". (Dalgarno & Riordan, 2014). "you think back, how could I have managed it differently, how, what did I do wrong, did I not pick up the signs as quickly as I should." (Storey et al., 2012).
Controlled and uncontained.	5	1, 3, 4, 6, 8.	"It depends who is in power at the moment how we are treated Consultants have complete power. We have nothing". (Huet, 2011). "the most stressful things that happens to the staff is to realise there's only two of us that know what we're doing, and the rest are bank it's heart breaking and that stresses the staff out a lot worse than a fight, and they are not empowered to do anything about it."". (Storey et al., 2012). "I had a client he came into the office and tried to get a knife Police came and wouldn't take him I had to stay in this house alone for another two hours, with someone who just tried to get a knife to stab me." (Coates & Jones, 2019). "I feel like [Transforming Care] police the CPA process." (Hudson et al, 2021).
'We just didn't have a clue'	5	2, 4, 5, 6, 8.	"I've had, basic training on personality disorders, but never any sort of specialised training, in regards to people with personality disorder and intellectual disability". (Zarotti et al., 2020). "The patient group is chaotic by the nature of their needs, but because you haven't got the evidence base to support your knowledge, it becomes more chaotic. You're not always certain about the things that you're doing are right." (Dalgarno & Riordan, 2014). "T'm not actually 100%, er, I couldn't tell you what the clinical definition of personality disorder is." (Lee & Kiemle, 2015). "We just didn't have a clue" (Storey et al., 2012).

Themes	Number of studies	Studies	Example Quotation (source)
Subthemes	reporting		
			"when we do have psychiatry, we're very dependent upon that individual psychiatrist and their training and their confidence" (Zarotti, 2022). "I never had any training and my initial thoughts on the job were almost as a custodial type person, keep them locked up and don't expose them to any risk", Dalgarno & Riordan, (2014). "There is a course, I think we're all crying out to get on it yeah, and it is needed, it is." (Lee & Kiemle, 2015).
Marginalised	5	1, 2, 3, 4, 8	"We are employed to keep these difficult people out of everyone else's way. Everyone is paying for them to be there but would rather not know the "ins and outs" of it'." (Huet, 2011). "Tve sat with girlfriends at the end of the week and had a catch up; I can't talk about my work. It's probably here that you know that people understand what you do and the challenges that the staff face on the ground day to day." (Coates & Jones, 2019). "There's a lot of research going on still in those areas [non- forensic LD MH] you know, physical health, person centred planning whereas forensic base, there isn't that much activity." (Dalgarno & Riordan, 2014). "If I talk to someone about something that has happened at work, people are really shocked by it. To me it is something you see every day." Huet, (2011). "When we go to the crisis team, they're like, 'well, you're under the intellectual disability team', so, 'no-thank-you' sort of attitude, which is not helpful" (Zarotti et al., 2022). "Tve had a lady who () has suspected emotionally unstable personality disorder and the social worker sort of said that she struggles working with people with personality disorders. () So, I do feel like her having that label has meant that she's not getting as much of a service as she should", (Zarotti et al., 2022).
'You don't seem to move forwards'	5	1, 2, 3, 5, 8	"I've been in meetings where three months later I'm sat in the same meeting again and there's no further progress" (Hudson et al., 2021).

Themes Subthemes	Number of studies reporting	Studies	Example Quotation (source)
			 "by the time the first e-mail gets from one person to where it's supposed to be at six months have gone by" (Hudson et al., 2021) "Erm, it can be quite tiring cos obviously, a lot of the behaviours are repeated, over and over It can feel quite hard cos you don't seem to move on from things and move forwards." (Lee & Keimle, 2014). It [should be] sort of a no closed doors approach (). If you've got a mild intellectual disability, you should have access to generic services, which on paper looks absolutely spot on." (Zarotti, et al., 2022) "You come to a recognition that their offence cycles haven't changed, they're still just as risky as they were, they're just in a different environment so that they can't present those behaviours" (Dalgarno & Riordan, 2014) "There's a lot of research going on. [in non-forensic LD MH] you know, physical health, person centred planning, whereas forensic base, there isn't that much activity." (Dalgarno & Riordan, 2014). "So I don't know whether we'll go full circle. Maybe in a couple of years' time we'll be back with all these beds open. And being in institutions again or whether [pause] other than that I don't know. We may go full circle" (Hudson et al., 2021).

Synthesis of the literature

A thematic synthesis was conducted on eight studies produced from a systematic search of the literature. This yielded seven themes and 11 subthemes, which are outlined in detail in Table 5 and summarised in Table 6.

Table 6:

Themes and Subthemes from	Thematic Synthesis
---------------------------	--------------------

Themes	Subthemes
1) 'Nobody liked her'	 'the majority are compulsive liars': Problematic Personalities 'She pushed my buttons': Complex Relationally 'Overshadowed': Complex Presentations 'Everyone had tragic lives'
2) 'An involved kind of role'	 'There's lots of considerations' 'Trying to support whilst restricting'
3) 'They tie you up in knots'	 'it's quite frustrating' 'I am always looking over my shoulders' 'a boiling pot of chaos': Overwhelm 'I put on a good show': concealing emotion 'How did I fail this person?'
4) Controlled and uncontained.	
5) 'We just didn't have a clue'	
6) Marginalised	
7) 'You don't seem to move forwards':	

'Nobody liked her'

The most dominant theme across all studies was that this group was particularly challenging to work with, across a variety of factors. An interesting phenomenon in the data was that the emphasis was heavily imbalanced toward personality disorder, such that little content related to the clients' intellectual disability. There was a trend among the studies to use negative language to describe the clients at explicit levels, i.e., "*I always found people [with] personality disorder as quite narcissistic*" (Lee & Kiemle, 2015), or implicit levels "*I was surprised at the support the patients had for each other*' (Taylor & Trout, 2013).

<u>'The majority are compulsive liars': Problematic Personalities:</u> A trend among the data was that people within this population were perceived as "*not always the most likeable people*", with descriptions such as '*manipulative*', '*liars*' and '*lacking in empathy*' used to describe them (Hudson et al., 2021; Lee and Kiemle, 2015).

<u>'She pushed my buttons': Complex Relationally:</u> This subtheme spoke to the relational difficulties that were described as endemic to working with this population, with little or no emphasis on the role of the clients' ID, in which clients were described as problematic or even harmful in relationships (Coates & Jones, 2020; Huet, 2011; Storey et al., 2012) either in terms of assault, abuse, or 'splitting' the team (Zarotti et al., 2022), as if this was a conscious rather than unconscious process. There was a pervasive sense across the literature of needing to be '*wary developing a relationship*' with a person with PD (Lee & Kiemle, 2015; Zarotti et al., 2022).

'Overshadowed': Problematic Presentations:

The intersection between the clients' ability and personality needs was more prominent in this subtheme. This was discussed in relation to how people with ID may struggle more to understand boundaries outlined by leave restrictions or societal expectations (Coates & Jones, 2020; Dalgarno & Riordan, 2014). There were also explicit suggestions that it was more difficult and problematic to work with a person with ID who was more able, as they were more skilled in being obstructive (Dalgarno & Riordan, 2014; Zarotti et al., 2022). A prominent theme, particularly in Zarotti and colleagues (2022) was the layers of complication that dual diagnoses presented across the spectrum of effective care, either in terms of

identification of PD being complicated by overlap with ID traits, or barriers in communication complicating the assessment process. It was apparent from descriptions in the data that the LD diagnosis overshadowed the PD diagnosis to such an extent that getting specialist support for personality disorder or crisis intervention was difficult or impossible: *"If you already got an intellectual disability diagnosis, then your chances of getting someone*

into a specialist PD service immediately go through the floor", (Zarotti et al., 2022).

Conversely, prejudice related to the 'PD' label was also described as having a blocking effect on effective care, "I do feel like her having that [PD] label has meant that she's not getting as much of a service as she should... the social worker sort of said that she struggles working with people with personality disorders", (Zarotti et al., 2022). It seemed that overshadowing was happening alternately in terms of ID and PD diagnoses, compounding the disadvantages for the individual in need of care, which also manifested in the participants' experiences of being alone in the caring role.

'Everyone had tragic lives'

A significant minority of the studies acknowledged the high levels of trauma and tragedy that were endemic to this population, which was typically connected to expressions of empathy and compassion (Coates & Jones 2020; Lee & Kiemle, 2015).

'An involved kind of role'

'There's lots of considerations'

A prominent theme across studies was how involved and varied the demands of the role were. This spanned crisis medical support (Lee & Keimle, 2015), managing high risk (Coates & Jones 2020; Huet, 2011; Storey et al., 2012; Zarotti et al., 2022) and high needs for emotional support (Dalgarno & Riordan, 2014; Huet, 2011; Storey et al., 2012; Zarotti et al., 2022), advocacy (Coates & Jones 2020; Zarotti et al., 2022), in addition to meeting mental health needs with the necessary adaptations for people with additional learning and communication needs (Coates & Jones 2020; Dalgarno & Riordan, 2014; Zarotti et al., 2022). <u>'Trying to support whilst restricting':</u>

A theme that was evident in most studies was that the needs of the individual service user were nearly always in tension with needs of the service, or in the case of forensic clients, public protection (Coates & Jones 2020; Dalgarno & Riordan, 2014; Hudson et al., 2021; Lee & Kiemle, 2015; Zarotti et al., 2022). This came in the form of recognising the need for positive risk taking, whilst feeling a duty to protect the public from potential harm. Another example was the service users' high needs for closeness and intimacy, and explicit references to staff remaining emotionally remote to cope with the demands of the work (Lee & Kiemle, 2015; Huet, 2011; Storey et al., 2012; Zarotti et al., 2022). The management of these dilemmas were expressed as being a point of tension among the MDTs and that it was difficult to reach consensus or compromise (Dalgarno & Riordan, 2014; Storey et al., 2012; Zarotti et al., 2022).

'They tie you up in knots'

The majority of studies referenced a significant emotional toll related to their work. The only study that did not allude to this was Taylor and Trout (2011), for which negligible direct source material was provided. One of the themes was titled' Team cohesion and stress', in which 'support' of one another in the team referenced as a 'concern', however, making robust inferences in relation to the emotional experiences of the participants beyond this was not possible.

'It's quite frustrating'

Frustration was the most common emotion expressed in the data, and it was evident across different aspects of the role in all studies, bar Taylor and Trout (2014). Participants relayed how hemmed-in they felt by legal or organisational boundaries that constricted the reach of

their therapeutic efforts, such that there was a sense that the employee was ineffectual against the larger institutional machine (Coates & Jones 2020; Dalgarno & Riordan, 2014; Hudson et al., 2021; Lee & Keimle, 2015; Storey et al., 2012; Zarotti et al., 2022). Feelings of frustration also related to the repetitious and cyclical nature of some of the behaviour that challenged the participants, such that progress felt glacial or out of reach (Coates & Jones 2020; Dalgarno & Riordan, 2014; Lee & Keimle, 2015). Another prominent pattern across most studies related to cumbersome bureaucratic interagency processes that left participants felt irritated and impotent to effect change or progress a person's care (Coates & Jones 2020; Dalgarno & Riordan, 2014; Zarotti et al., 2022).

'I am always looking over my shoulders'

Fear was a striking emotion that emerged from most studies, relating to past, present and future feared catastrophes, with all studies referencing it, with the exception of Taylor and Trout (2014). Historic offences committed by clients and 'dramatic events' that lived on in infamy in the lore of the wards were referred to as causing feelings of unease and intimidation (Dalgarno & Riordan, 2014; Huet, 2011). There was a sense of fragility in relation to safety, in that sudden and unexpected violence was a constant threat and that the individual staff member ultimately held responsibility for their own safety (Huet, 2011; Hudson et al., 2021; Storey et al., 2012; Zarotti et al., 2022). Constant vigilance was therefore outlined as a defence against abuse or significant physical harm. Anxiety also related to feared future outcomes related to public safety and feeling manoeuvred into making decisions against clinical judgement, such as pressure to discharge in relation to TC mandates (Dalgarno & Riordan, 2014; Hudson et al., 2021).

'A boiling pot of chaos': overwhelming:

The sense that participants were pushed to limits of their emotional tolerance was expressed in several studies, either in their description of their role as frantic and difficult to cope with,

or their accounts of cutting off from traumatic events (Huet, 2011; Lee & Keimle, 2015; Storey et al., 2012).

'I put on a good show': concealing emotion

A fascinating pattern across several studies was the sense that it was imperative to mask one's fear or uncertainty (Huet, 2011; Lee & Keimle, 2015; Storey et al., 2012). The pretence of calm was expressed as essential to safety, but left some of the participants with feelings of dissonance around what was being supressed or disingenuously represented (Huet, 2011; Storey et al., 2012).

'How did I fail this person?'

A sense of failure and responsibility in relation to clients being stepped up in security, or the participant themselves being involved in a serious incident was expressed in two papers (Dalgarno & Riordan, 2014; Storey et al., 2012). These expressions of regret and self-reproach were often related to not having predicted or prevented negative events.

Controlled and uncontained

Overseeing bodies and senior team members were experienced as remote, insensitive or unhelpful in most of the studies, with the exception of Dalgarno and Riordan, (2014) and Taylor and Trout, (2014). This was described in relation to those at the apex of the hierarchies on the ward not responding to the needs of the staff members on the 'coal face'. This was described in relation to structural decisions, such as in Storey et al., (2012) in which overtime was banned for substantive staff against the wishes of the nursing and support work teams, resulting in unstable and unskilled teams. A similar sense of powerlessness was communicated by Huet (2011) in that consultants had 'complete power... we have nothing'. Some studies described overseeing bodies as overbearing, but not supportive or containing (Coates & Jones, 2020; Hudson et al., 2021). An ambivalence to support was also voiced in Storey et al. (2012), rooted in a lack of trust.

'We just didn't have a clue'

A prominent theme among the papers was that participants did not feel as though they had the necessary knowledge or expertise to do their role appropriately, placing particular emphasis once more on PD (Dalgarno & Riordan, 2014; Huet, 2011; Lee & Kiemle, 2015; Storey et al., 2012; Zarotti et al., 2022). A sense that knowledge was centralised was reminiscent of previous themes of powerlessness (Lee & Kiemle, 2015; Zarotti et al., 2022). There was a sense that this added to the stress, insecurity and confusion felt within the role (Dalgarno & Riordan, 2014; Huet, 2011; Lee & Kiemle, 2015; Storey et al., 2012; Zarotti et al., 2022). There was an expression of appetite for increased knowledge across some studies and a desire to expand understanding and expertise (Lee & Kiemle, 2015; Zarotti et al., 2022).

Marginalised

A common theme that arose across the studies was a sense that there was a peripheral, siloed nature to the experience of the participants working in this area (Coates & Jones, 2020; Dalgarno & Riordan, 2014; Huet, 2011; Hudson et al., 2021; Zarotti et al., 2022). In personal terms, friends and family did not understand or relate to the work (Coates & Jones, 2020; Huet, 2011). This was also apparent in terms of a sense of being forgotten by society (Huet, 2011). There was a sense that the clients were unwanted from society, placing the expressed aim of most of these services and their employees at odds with the wider world (Dalgarno & Riordan, 2014; Hudson et al., 2021). There were misgivings expressed that this population was forgotten by the scientific community, which added to the sense that they were alone in working it out (Dalgarno & Riordan, 2014). There was also a sense of loneliness within the teams themselves, due to schisms between support staff and management (Huet, 2011; Storey et al., 2012; Taylor & Trout, 2014), and a sense that the individual participants were

ultimately alone in maintaining their safety (Coates & Jones, 2020; Dalgarno & Riordan, 2014; Huet, 2011; Hudson et al., 2021).

Participants in Zarotti and colleagues (2022) expressed a sense of being disconnected from making links or obtaining support from other organisations, by virtue of the clients' ID, which resulted in rejection from specialist trauma or PD services. Discrimination on the basis of clients' PD diagnosis was also referenced as resulting in closed doors, such that prejudice was evident in the systems around the individual in need of care (Zarotti et al., 2022). The culmination of these factors gave the sense of a workforce who were working on the fringes of society and of services, without community or connection.

You don't seem to move forwards'

A sense of stasis and stagnancy permeated several of the studies (Coates & Jones, 2020; Dalgarno & Riordan, 2014; Hudson et al., 2021; Lee & Kiemle, 2015; Zarotti et al., 2022). This was related to a sense of impotence in effecting change in therapeutic terms, and a sense of being encumbered by inefficient and glacial interagency working (Coates & Jones, 2020; Dalgarno & Riordan, 2014; Hudson et al., 2021). Hudson and colleagues (2021) also remarked on pressure to discharge clients, but with a sense that there was nowhere for the client to go, with a dearth of appropriate placements or facilities, and an indifferent society at best to greet them. A sense of futility and frustration was expressed by in this paper with the cyclical nature of deinstitutionalisation. There was also a sense that there was a lack of empirical interest and innovation in the field, which contributed to a sense of inertia (Dalgarno & Riordan, 2014).

Discussion

To explore the experiences of staff working in care or clinical roles with people with ID and PD or cPTSD, a systematic literature search was conducted to identify and collate available data. Eight studies were identified, which were subjected to a thematic synthesis. The

analysis identified seven themes, which were: 'Nobody liked her'; 'An involved kind of role'; 'They tie you up in knots'; Controlled and uncontained; 'We just didn't have a clue'; Marginalised; You don't seem to move forwards'. 11 subthemes were also identified, which are discussed in further detail below. There was a cohesion in the narratives across studies, particularly in terms of the role and clinical context as complex across observable strata.

'Nobody liked her'

Some troubling patterns arose in this theme, the most consistently occurring across studies, which evoked a sense that the service users were not particularly liked or valued by participants. There was a sense in some of the content that processes of mentalisation or empathy were shut down in participants, which is a fascinating mirroring of key deficits that are typical of 'borderline PD' presentations (Bateman & Fonagy, 2010). The term PD has been described as an intellectual 'dumping ground' for emotions, behaviours and experiences that are too difficult to think about (Anderson et al., 2020). The prejudice in the data speaks to a disconnection from a sense that the service users are doubly vulnerable survivors of trauma with many layers of oppression and disadvantage related to having an ID. Wright and colleagues (2007) noted that staff responses to people with PD diagnoses can be swayed from a clinical focus ("this person is traumatised"), to a moral one ("this person is bad") with detrimental effects on quality of care and therapeutic relationships. In her work with this client group, Frankish (2018) describes how staff reacting to client distress may themselves feel distressed or angry, which may shift the focus to their own emotional safety, and away from the service users', which may have been at play considering the dehumanising descriptions used. It may speak to a psychological defence in care settings in which dehumanisation protects the employee charged with caring for the client from anxiety and distress (Menzies Lyth, 1988). This theme was ubiquitous across studies, the quality of which varied. That said, the overall body of literature was strong, which lends more credibility to this finding.

The relational landscape of the service users was presented as barren and volatile. There was a longing and loneliness that came forth in the data that was perceived by participants. A sense of anxiety emerged in relation to intense attachment-seeking behaviour and high emotional expectations, which was as prominent as anxiety related to abusive or violent behaviour. These themes emerged from studies of sound quality overall (Dalgarno & Riordan, 2014; Huet, 2011; Storey et al., 2012), which gives one greater confidence in their validity. "Attach-attack" disorganised attachment patterns are indicative of high levels of relational trauma in the client group, which begs reflection on potentially retraumatising environments in which service users are devalued, disempowered, invalidated and unable to escape from authority attachment figures (Perez et al., 2020; Sweeney et al., 2018), particularly if they are under section of the mental health act or on remand for a crime.

The complexity of the clinical population was raised in several of the studies, in which the service users' high level of ability, though still intellectually disabled meant that they were inhabiting the space between a rock and a hard place clinically, for several reasons. The clients were described as 'tricky' to manage, presented in terms of being skilled in introducing obstruction and chaos to care plans and team dynamics, such that their relatively high intellectual ability was not portrayed as a strength. This tricky level of ability meant that service users often fell under thresholds for the degree of support they needed from social services. A fascinating pattern in the data from studies of good quality was that ID was reported as having an overshadowing effect on PD (Dalgarno & Riordan, 2014; Zarotti et al., 2022), which enabled gatekeeping from specialist or mainstream services and resulted in closed doors and missed opportunities to address the individuals' trauma and personality difficulties. This manifest content was at direct odds with the process across studies, in which

negligible consideration was given to the service users' ID, such that the tribulations of working with people with PD eclipsed overt references to ID. The observation of PD overshadowing ID as a psychological process was identified explicitly in the discussion of Lee and Kiemle (2015), who noted this despite equal emphasis on ID and PD in their interview questions. This process was observed in the synthesis also across studies, the quality of which was strong with one exception. This may speal to a broader phenomenon in which holding the service user in mind in their entirety is too difficult, and in its place a fragment of their personhood is instead focused on, a psychological process which is typical of people with BPD (Fuchs, 2007).

'An involved kind of role'

The breadth of responsibilities spanning complex individual care, team dynamics and negotiating complex and conflicting priorities was prominent in the experience of the participants. The role was presented as very demanding and dynamic, although there was a pervasive lack of confidence accompanying this theme which gave a frantic overall impression of the experience. Seemingly quotidian aspects of the role were confronting to read, such as providing emergency medical aid following self-injury, managing conflict in high-risk environments and the cognitively, ethically, and emotionally burdensome task of positive risk-taking. This theme was drawn from studies of high quality, which gives one greater confidence in its credibility. The participants expressed experiences of being pulled in many directions, such that at times it felt like their professional goals were at odds with one another. The cumulative repetition and reiterations of dilemmas in care and allegiances led to a sense of a split professional identity, lacking in congruence or resolution, once more reminiscent of the unstable identity, a hallmark of people labelled with 'BPD' (Luyten et al., 2020).

'They tie you up in knots'

The emotional intensity of working in this domain emerged vividly from most studies, all of which were of good or excellent quality. The only study for which it was absent was Taylor and Trout (2011), in which the vast majority of manifest content was not reported, which raises questions regarding what is being consciously or unconsciously avoided in these participants' experiences.

High levels of fear, distress and frustration were evident in the data. The aggregation and reading of the manifest content was a visceral experience, and it elicited feelings of empathy in the author that hitherto had been overshadowed by concern and frustration on behalf of the service users. The parallels with traumatised behaviour were evident in this theme also, in which overwhelming intense feelings of fear or anger were at times too much for the participants to bear. The coping mechanisms in the text were dissociative in nature, 'vou've got to switch off, you've got to switch off, you've got to switch off' (Storey et al., 2012) reminiscent once more of borderline defences of unbearable or overwhelming emotions (Fonagy & Target, 1997). The expression that one needed to 'fake' confidence in the face of fear and uncertainty, the disconnection between what was felt and what was portrayed was reminiscent of 'masking', a phenomenon in ID and autism in which an individual camouflages their difficulties and portrays a greater sense of understanding or control to protect themselves from negative social or relational experiences (Hull et al., 2017). There was a sense of pretence going in both directions, which added to the sense of relational remoteness and instability. It is also the case that the level of childhood trauma in healthcare workers is high (Maunder et al., 2010), which indicates that staff themselves can potentially be retraumatised by the work setting.

Controlled and uncontained

Authority figures and overseeing bodies were perceived as controlling and misattuned to the needs of the participants. Potency and agency seemed to be located in team management, to the extent that a pervasive sense of powerlessness and resentment was present in the data, reminiscent of dependent group assumption in which a 'parent-child' dynamic is re-enacted (Bion, 1961). The sense that participants were controlled, dismissed, but not taken care of or given emotional containment, conjured an image of the institutions of yore in which the service users benefitted from neither liberty nor safety. A sense of voicelessness in manifest content was poignantly illustrated in the erasure of the nurses' voices in Taylor and Trout (2013), which could be understood as a re-enactment of this silencing. This is more poignant still when one considers the context in which that study occurred, a therapeutic community for which flat hierarchies and empowerment are ethical pillars, yet the researcher (who was a senior clinician in that environment), drowned all others out. The domineering and paternalistic act of speaking over and speaking for whilst being an outsider to the experience itself is reminiscent of what was being rejected in the 'Nothing about us without us' movement (Franits, 2005). The quality of Taylor and Trout (2013) was poor, therefore this interpretation must be considered with caution. The quality of the other papers which contributed to this theme were either good or excellent, which lends the findings more credibility.

The conditions outlined above are not conducive to fostering a reflective or empathic workforce. Chronic and repeated stress in the workplace in which employees do not feel safe or trusting of their organisation can result in unhealthy and cynical environments in which trauma is re-enacted (Bentovim, 1992; Bloom, 2004) The hostile and helpless position held by many of the participants in relation to authority figures was indicative of insecure or disorganised attachment (Braun, 2011; Pearlman & Courtois, 2005), in which the parallels

with BPD are continued. It was apparent that the teams were incomplete and unstable, with inadequate staffing and absent management or leadership. A fascinating reflection in Storey et al., (2012) was that the participants would react suspiciously and defensively if support or space for reflection was offered. Moreover, it was an explicit recommendation that professionals would be unwise to disrupt participants' defence mechanisms, as it could be harmful to unravel those defences if the environment was not safe enough to survive without them (Obholzer, 1986).

'We just didn't have a clue'

It was apparent from the data that participants believed it was important to have specialist knowledge or training in relation to PD. It was also vividly expressed that the participants did not believe they held this knowledge or expertise, with some expressing they did not know that they were working with people with PD or what this meant. The sense of incompetence and accompanying anxiety was an acknowledged with a sense that one 'just had to work it out'. ID was notable for its absence in this conversation, it was only acknowledged in one quote in Zarotti and colleagues (2022). Why the clients' ID was overlooked in this context unclear.

Considering the degree of vulnerability and complexity in this patient group, it is remarkable that there is so little clinical confidence emerging in the data. A sense of uncertainty in one's own skills and in the right course of action, in conjunction with the lack of trust in leadership or one's team in a high stress environment are key risks in sustaining moral injury and burnout in the workplace (Dean et al., 2019; Freudenberger, 1975), demonstrating how vulnerable this groups' wellbeing is. The data from which this theme emerged was from studies of good or excellent quality, giving one greater confidence in drawing inferences, if still tentatively, from the data.

Marginalised

There was a sense that this participant group were working on the fringes of society and of mental health and care services. The idea that people with ID and PD are unwanted and not valued in society appeared to inhabit the participants' experiences (Sinclair, 2018; Wolfensberger, 1982). The sense of being in some way set apart by their professional experiences was apparent in terms of how participants did not feel understood by their friends or family. The question "What do you want to do this job for?" (Huet, 2011) was a striking example, for which was no answer in the data of that paper, or the other papers. There were no allusions to the rewarding aspects or motivations to do the role. There was a sense that that their work and therefore their experiences were taboo, reflected to them by horrified and incredulous reactions to things 'we see every day' (Huet, 2011). This sense of being siloed or peripheral was also apparent in the difficulties expressed in linking with other specialist services for trauma or PD. The description of the clients as particularly able would indicate that they would be able to access adult specialist services with reasonable adjustments (Equality Act, 2010), yet this did not seem to be facilitated in the data. There was also a sense of being forgotten by the empirical community, as the lack of research and therefore good practice guidance, which added to the sense of abandonment, where the parallels with BPD are continued. This theme emerged from data with good or excellent quality ratings, which lends credence to its validity.

'You don't seem to move forwards'

Most studies happened against a backdrop of seismic structural or organisational changes in care, such as legislative reform of social welfare benefits, internal restructuring within services and deinstitutionalisation mandates in the wake of Transforming Care; despite this, a sense of stuckness and timelessness permeated the data. A sense of arrested development in terms of neglect from the research was a component of this, as was the sense that reform

mandates from Transforming Care were cyclical and futile, '*We may go full circle*' (Hudson et al., 2021). This may speak to a perceived naïveté that removing or closing institutions would solve the problems that occurred within them, when in fact they are relocated, rebranded and repeated. The sense that a 'one size fits all' national strategy was out of touch and problematic was apparent in studies which occurred in the UK and Australia, and were not perceived progressive and were in some ways perceived as regressive. There was a sense of hope and positivity expressed in some of community services in Hudson et al. (2021), which was at odds with the inpatient group, for whom progress may have felt less tangible. In general, across studies the sense of progress being out of reach was palpable, which was partly related to the complexity of the client group. Sluggish and obstructive bureaucratic processes also fed into this, in which it felt months and years vanished without change. This theme was developed from studies with good or excellent quality ratings, giving one greater confidence in their validity.

The extent to which hallmarks of the borderline experience are reflected in the data was striking. Splitting as a defence mechanism is considered a response to how a child internalises aspects of their parental object that they cannot integrate, such as when the person on whom they are dependent for survival is frightening or dangerous to them (Klein, 1946). This can be re-enacted in care teams when the team or institution are related to as parental objects in the transference, which cascades to how the participants appeared to relate to authority figures; represented primarily as 'bad objects' in the data. The other reason for the vivid mirroring between the BPD and participant experiences may have been because of the psychological defence of projective identification, in which the intolerable feelings unconsciously held by the client are projected into care/ nursing staff, who then identify with these projective phenomena as though they are their own and carry some of the clients'

experience. This speaks to inadequate reflective or supervision spaces to support the staff to metabolise and make sense of these experiences (Obholzer, 1986).

Clinical Implications:

The data demonstrate that this population of staff appear to be traumatised. It is apparent that aspects of the role are traumatic in and of themselves, both in terms of direct and vicarious victimisation. Furthermore, a pervasive sense of having inadequate training and expertise was present. This is important to consider for several reasons. The role of a resilient and competent workforce is of particular significance in the realm of ID, considering the degree of vulnerability in the population, coupled with greater dependence on members of staff for good quality of life and of care (Schuengel et al., 2013).

The participants in the review were largely mental health and allied professionals, many of whom would have had at least degree level training, continued professional development opportunities and some degree of clinical supervision as standard. It is important therefore to consider how the findings may relate to care staff with less training or status, such as health care assistants or support workers, who represent a significant proportion of people on the frontline of care services. It is incumbent on care providers to note the degree of stress and cynicism in the data when considering frontline care staff needs in terms of training, supervision and support.

Advances in trauma-informed research in the field of ID have been developing to meet the challenges outlined above. National and global movements toward systemic traumainformed working are seeking to improve the clinical landscape for service users and staff members alike, (Keesler, 2014; Rich et al., 2021; Rye et al., 2021; Truesdale et al., 2019). A recommendation put forth by Frankish (2018) to safeguard the health of teams and enhance the care provided, is to build skills in self-reflection, scaffold psychological understanding of the challenges that arise in caring for traumatised individuals and to recognise

countertransference reactions. This appears to be vitally important considering how present these phenomena were in the data.

Research Implications

The experiences of staff working with people with ID and PD/cPTSD is poorly understood and underserved empirically, therefore there are many avenues of advancing knowledge in this field.

Research exploring factors related to resilience and reflection in this population would be beneficial in guiding future interventions aimed at supporting wellbeing, competence, and improving quality of care.

Support workers and healthcare assistants make up a significant subgroup of people who care for people with ID and complex needs related to trauma, however, their experiences were not explored or represented in the review, as research of this nature does not appear to exist, or was not identified. This represents a significant gap in the literature. Comprehensive explorations of this groups experiences, needs, challenges and sources of resilience is urgently needed to help shape and guide this developing field.

Limitations

Due to the difficulties presented by the heterogenous and euphemistic terminology related to ID and PD, it cannot be claimed that the present review is an exhaustive analysis of all qualitative literature in the field of staff experiences of their role. The research in the area is not extensive, and as such, conclusions drawn are tentative, particularly as the included studies are imperfect and of varying quality. A defining weakness of the database is that little about the demographic is known, which limits the generalisability of the findings. Additionally, the review is two steps removed from the participants' experiences and is thus subject to multiple layers of bias in which important nuances may have been lost.

Furthermore, the author has experience of working in this area, which may have biased her analysis and influenced the results.

Conclusion

History has demonstrated time and again that the ID population, particularly those with personality or trauma disorders, are particularly vulnerable to abuse and marginalisation. The restructuring and rebranding of institutional care that came with TC has been met with some scepticism from those who posit that the institution is not the evil, rather it is an instrument of an indifferent society (Clegg, 2008; Zenderland & Trent, 1995) and it was sobering to see how much distress and cynicism was present for these staff members. It was apparent that the need for reform is ongoing. It is unlikely that safe and therapeutic space can be created for service users if the health, resilience and expertise of teams is not prioritised, therefore this should be emphasised and prioritised in service planning and delivery going forward.

References

- Alexander, R., & Cooray, S. (2002). Diagnosis of personality disorders in learning disability. *The British Journal of Psychiatry*, 182(S44), s28-s31. https://doi.org/10.1192/bjp.182.44.s28
- Alexander, R. T., Chester, V., Gray, N. S., & Snowden, R. J. (2012). Patients with personality disorders and intellectual disability–closer to personality disorders or intellectual disability? A three-way comparison. *Journal of Forensic Psychiatry & Psychology*, 23(4), 435-451. https://doi.org/10.1080/14789949.2012.6944622
- Andersen, H. K. (2015). Personality disorder and intellectual disability–concept and prevalence. Advances in Mental Health and Intellectual Disabilities, 9(4), 163-173. https://doi.org/10.1108/amhid-05-2015-0019
- Anderson, J., Pickard, M., & Rye, E. (2020). *The CaPDID training manual: A traumainformed approach to caring for people with a personality disorder and an intellectual disability.* Pavilion Publishing.
- Aviram, R. B., Brodsky, B. S., & Stanley, B. (2006). Borderline personality disorder, stigma, and treatment implications. *Harvard Review of Psychiatry*, 14(5), 249-256. https://doi.org/10.1080/10673220600975121
- Bateman, A., & Fonagy, P. (2010). Mentalization based treatment for borderline personality disorder. *World Psychiatry*, 9(1), 11 15. https://doi.org/10.1002/j.2051-5545.2010.tb00255.x
- Bentovim, A. (1992). Trauma-organized systems: Physical and sexual abuse in families. (1st ed.) Routledge. https://doi.org/10.4324/9780429484315

Bion, W. R. (1961). Experiences in groups: And other papers. (1st Ed.). Tavistock.

- Bloom, S. L. (2004). Neither liberty nor safety: the impact of fear on individuals, institutions, and societies, part I. *Psychotherapy and Politics International*, 2(2), 78-98. https://doi.org/10.1002/ppi.75
- Braun, G. (2011). Organisations today: What happens to attachment?. *Psychodynamic Practice*, *17*(2), 123-139. https://doi.org/10.1080/14753634.2011.562692
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health*, 21(1), 87-108. <u>https://doi.org/10.1080/14768320500230185</u>
- Clegg, J. (2008). Holding services to account. *Journal of Intellectual Disability Research*, 52(7), 581-587. https://doi.org/10.1111/j.1365-2788.2008.01068.x
- Cloitre, M., Garvert, D. W., Weiss, B., Carlson, E. B., & Bryant, R. A. (2014). Distinguishing PTSD, complex PTSD, and borderline personality disorder: A latent class analysis. *European Journal of Psychotraumatology*, 5(1), 25097. https://doi.org/10.3402/ejpt.v5.25097
- Coates, B., & Jones, T. (2020). A qualitative analysis of the experience of staff employed within the forensic disability sector in Victoria, Australia. *Journal of Applied Research in Intellectual Disabilities*, 33(4), 757-766. https://doi.org/10.1111/jar.12611
- Cook, S., & Hole, R. (2021). Trauma, intellectual and/or developmental disability, and multiple, complex needs: A scoping review of the literature. *Research in Developmental Disabilities*, 115, 103939. https://doi.org/10.1016/j.ridd.2021.103939

- Cooray, S. E., Alexander, R., Purandare, K., Chester, V., & Tyrer, P. (2022). Personality disorder in people with intellectual disability or those with intellectual disability and autism spectrum disorder. In M. O. Bertelli, S. Deb, K. Munir, A. Hassiotis, L. Salvador-Carulla (Eds.) *Textbook of Psychiatry for Intellectual Disability and Autism Spectrum Disorder* (pp. 807-823). Springer International Publishing.
- Critical Appraisal Skills Programme (2018). *CASP Qualitative Research Checklist*. <u>https://casp-uk.net/casp-checklists/CASP-checklist-qualitative-2024.docx</u>
- Dalgarno, M. F., & Riordan, S. A. (2014). Forensic learning disability nursing: what's it really like? *Journal of Intellectual Disabilities and Offending Behaviour*, 5(4), 167-177. <u>https://doi.org/10.1108/JIDOB-11-2014-0017</u>
- Dean, W., Talbot, S., & Dean, A. (2019). Reframing Clinician Distress: Moral Injury Not Burnout. *Federal Practitioner*, 36(9), 400–402.
- Emerson, E., & Baines, S. (2010). The estimated prevalence of autism among adults with learning disabilities in England. *Improving Health and Lives: Learning Disabilities Observatory*. <u>https://www.talkingaboutthescience.com/studies/Emerson2010.pdf</u>
- Emerson, E., & Einfeld, S. (2011). *Challenging Behaviour* (3rd ed.). Cambridge University Press. https://doi.org/10.1017/CBO9780511861178
- Finfgeld-Connett, D. (2010). Generalizability and transferability of meta-synthesis research findings. *Journal of Advanced Nursing*, 66(2), 246-254.
 <u>https://doi.org/10.1111/j.1365-</u>2648.2009.05250.x
- Flynn, A., Matthews, H., & Hollins, S. (2002). Validity of the diagnosis of personality disorder in adults with learning disability and severe behavioural problems:
 Preliminary study. *The British Journal of Psychiatry*, *180*(6), 543-546.
 https://doi.org/10.1192/bjp.180.6.543

- Fonagy, P., & Target, M. (1997). Attachment and reflective function: Their role in selforganization. *Development and Psychopathology*, 9(4), 679-700. <u>https://doi.org/10.1017/s0954579497001399</u>
- Ford, J. D., & Courtois, C. A. (2021). Complex PTSD and borderline personality disorder. *Borderline Personality Disorder and Emotion Dysregulation*, 8(1). https://doi.org/10.1186/s40479-021-00155-9
- Franits, L. E. (2005). Nothing about us without us: Searching for the narrative of disability. *The American Journal of Occupational Therapy*, 59(5), 577-579. https://doi.org/10.5014/ajot.59.5.577
- Frankish, P. (2018). Disability psychotherapy: An innovative approach to trauma-informed care. Routledge. https://doi.org/10.4324/9780429473784
- Frankish, P. (2013). Facing emotional pain—a model for working with people with intellectual disabilities and trauma. *Attachment*, 7(3), 276-282.
- Freudenberger, H. J. (1975). The staff burn-out syndrome in alternative institutions. *Psychotherapy: Theory, Research & Practice*, 12(1), 73-82. https://doi.org/10.1037/h0086411
- Fuchs, T. (2007). Fragmented selves: Temporality and identity in borderline personality disorder. *Psychopathology*, 40(6), 379-387. https://doi.org/10.1159/000106468
- Gentile, J. P., Bhatt, N. V., Cannella, J. P., Harper, K., & Johnson, J. (2022). Personality Disorders in Patients with Intellectual Disability. *Innovations in Clinical Neuroscience*, 19(7-9), 17–21.
- Green, S., Davis, C., Karshmer, E., Marsh, P., & Straight, B. (2005). Living stigma: The impact of labelling, stereotyping, separation, status loss, and discrimination in the

lives of individuals with disabilities and their families. *Sociological Inquiry*, 75(2), 197- 215. https://doi.org/10.1111/j.1475-682X.2005.00119.x

- Halton, W. (1994). Some unconscious aspects of organizational life: contributions from psychoanalysis. In A. Obholzer, V. Zagier Roberts (Eds). *The Unconscious at Work*, (2nd ed., pp. 11-18). Routledge.
- Hudson, N., House, R., Robson, N., & Rayner-Smith, K. (2021). 'It's a good thing we're doing, we just need to be better at it'. Forensic intellectual disability nursing experiences of Transforming Care: A multi-perspectival interpretive phenomenological analysis. *Journal of Applied Research in Intellectual Disabilities*, *34*(4), 1066-1075. https://doi.org/10.1111/jar.12855
- Huet, V. (2011). Art therapy-based organisational consultancy: A session at Tate Britain. *International Journal of Art Therapy*, 16(1), 3-13. <u>https://doi.org/10.1080/17454832.2011.575382</u>
- Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & Mandy, W. (2017). "Putting on my best normal": Social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders*, 47(8), 2519-2534. <u>https://doi.org/10.1007/s10803-017-3166-5</u>
- Hyland, P., Karatzias, T., Shevlin, M., & Cloitre, M. (2019). Examining the discriminant validity of complex posttraumatic stress disorder and borderline personality disorder symptoms: Results from a United Kingdom population sample. *Journal of Traumatic Stress*, 32(6), 855-863. <u>https://doi.org/10.1002/jts.22444</u>
- Hyland, P., Shevlin, M., Fyvie, C., & Karatzias, T. (2018). Posttraumatic Stress Disorder and Complex Posttraumatic Stress Disorder in DSM-5 and ICD-11: Clinical and Behavioral Correlates. *Journal of Traumatic Stress*, *31*(2), 174-180. https://doi.org/10.1002/jts.22272

- Johnstone, L., & Boyle, M. (2018). The power threat meaning framework: An alternative nondiagnostic conceptual system. *Journal of Humanistic Psychology*. https://doi.org/10.1177/0022167818793289
- Jowett, S., Karatzias, T., Shevlin, M., & Albert, I. (2020). Differentiating symptom profiles of ICD-11 PTSD, complex PTSD, and borderline personality disorder: A latent class analysis in a multiply traumatized sample. *Personality Disorders: Theory, Research, and Treatment, 11*(1), 36–45. https://doi.org/10.1037/per0000346
- Keesler, J. M. (2014). A Call for the Integration of Trauma-Informed Care Among
 Intellectual and Developmental Disability Organizations. *Journal of Policy and Practice in Intellectual Disabilities*, 11(1), 34–42. https://doi.org/10.1111/jppi.12071
- Khan, A., Cowan, C., & Roy, A. (1997). Personality disorders in people with disabilities: a community survey. *Journal of Intellectual Disability Research*, 41(4), 324-330. https://doi.org/10.1111/j.1365-2788.1997.tb00716.x
- Klein, M. (1946). Notes on some schizoid mechanisms. *The Journal of Psychotherapy Practice and Research*, 5(2), 160.
- Lee, A., & Kiemle, G. (2015). 'It's One of the Hardest Jobs in the World': The experience and understanding of qualified nurses who work with individuals diagnosed with both learning disability and personality disorder. *Journal of Applied Research in Intellectual Disabilities*, 28(3), 238-248. https://doi.org/10.1111/jar.12125
- Lindsay, W. R., Steptoe, L., Hogue, T. E., Taylor, J. L., Mooney, P., Haut, F., Johnston, S., & O'Brien, G. (2007). Internal consistency and factor structure of personality disorders in a forensic intellectual disability sample. *Journal of Intellectual & Developmental Disability*, 32(2), 134–142. https://doi.org/10.1080/13668250701411412

- Luyten, P., Campbell, C., & Fonagy, P. (2020). Borderline personality disorder, complex trauma, and problems with self and identity: A social-communicative approach. *Journal of Personality*, 88(1), 88-105. https://doi.org/10.1111/jopy.12483
- MacIntosh, H. B., Godbout, N., & Dubash, N. (2015). Borderline personality disorder:
 Disorder of trauma or personality, a review of the empirical literature. *Canadian Psychology/Psychologie Canadienne*, 56(2), 227 – 241.

https://doi.org/10.1037/cap000028

- Malan, D., & Parker, L. (1995). Individual psychotherapy and the science of psychodynamics. CRC Press. https://doi.org/10.1201/b13307
- Maunder, R. G., Peladeau, N., Savage, D., & Lancee, W. J. (2010). The prevalence of childhood adversity among healthcare workers and its relationship to adult life events, distress and impairment. *Child Abuse & Neglect*, 34(2), 114-123. https://doi.org/10.1016/j.chiabu.2009.04.008
- McNally, P., Taggart, L., & Shevlin, M. (2021). Trauma experiences of people with an intellectual disability and their implications: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, 34(4), 927-949.

https://doi.org/10.1111/jar.12872

- Menzies Lyth, I. (1988) Containing Anxiety in Institutions: Selected Essays Volume One. Free Association Books.
- Naik, B. I., Gangadharan, S., & Alexander, R. T. (2002). Personality disorders in learning disability-the clinical experience. *The British Journal of Development Disabilities*, 48(95), 95-100. https://doi.org/10.1179/096979502799104210
- Nixon, M., Thomas, S. D., Daffern, M., & Ogloff, J. R. (2017). Estimating the risk of crime and victimisation in people with intellectual disability: a data-linkage study. *Social*

Psychiatry and Psychiatric Epidemiology, *52*(5), 617-626. <u>https://doi.org/10.1007/s00127-017-1371-3</u>

- Nunkoosing, K., & Haydon-Laurelut, M. (2012). Intellectual disability trouble: Foucault and Goffman on 'challenging behaviour'. In D. Goodley, B. Hughes, L. Davis (Eds) *Disability and Social Theory: New Developments and Directions* (pp. 195-211).
 Palgrave Macmillan. https://doi.org/10.1057/9781137023001_12
- Obholzer, A. (1986). Institutional dynamics and resistance to change. *Psychoanalytic Psychotherapy*, *2*(3), 201-206. https://doi.org/10.1080/02668738600700201
- Owczarek, M., Karatzias, T., McElroy, E., Hyland, P., Cloitre, M., Kratzer, L., Knefel, M., Grandison, G., Ho, G. W. K., Morris, D., & Shevlin, M. (2023). Borderline personality disorder (BPD) and complex posttraumatic stress disorder (CPTSD): A network analysis in a highly traumatized clinical sample. *Journal of Personality Disorders*, 37(1), 112-129. <u>https://doi.org/10.1521/pedi.2023.37.1.112</u>
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Aki, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S.,...Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *PLoS Medicine*, *18*(3). https://doi.org/10.1371/journal.pmed.1003583
- Pearlman, L. A., & Courtois, C. A. (2005). Clinical applications of the attachment framework: Relational treatment of complex trauma. *Journal of Traumatic Stress*, 18(5), 449-459. https://doi.org/10.1002/jts.20052

- Perez, S., Lorca, F., & Marco, J. H. (2020). Dissociation, posttraumatic stress symptoms, emotional dysregulation, and invalidating environments as correlates of NSSI in borderline personality disorder patients. *Journal of Trauma & Dissociation*, 21(5), 520-535. https://doi.org/10.1080/15299732.2020.1719262
- Pilgrim, D. (2001). Disordered personalities and disordered concepts. *Journal of Mental Health*, *10*(3), 253-265. https://doi.org/10.1080/09638230125289
- Pridding A,. & Procter N., (2008) A systematic review of personality disorder amongst people with intellectual disability with implications for the mental health nurse practitioner. *Journal of Clinical Nursing*. 17(21), 2811-2819.
 https://doi.org/10.1111/j.1365- 2702.2007.02269.x
- Rich, A. J., DiGregorio, N., & Strassle, C. (2021). Trauma-informed care in the context of intellectual and developmental disability services: Perceptions of service providers. *Journal of Intellectual Disabilities*, 25(4), 603-618.
 https://doi.org/10.1177/1744629520918086
- Rye, E., Anderson, J., & Pickard, M. (2021). Developing trauma-informed care: using psychodynamic concepts to help staff respond to the attachment needs of survivors of trauma. *Advances in Mental Health and Intellectual Disabilities*, 15(5), 201-208. https://doi.org/10.1108/amhid-12-2020-0033
- Schepens, H. R., Van Puyenbroeck, J., & Maes, B. (2019). "One does not forget, it all comes back": elderly people with intellectual disability review adversities and stressprotection in their lives. *Quality in Ageing and Older Adults*, 20(4), 190-205. https://doi.org/10.1108/qaoa-11-2018-0061
- Schuengel, C., de Schipper, J. C., Sterkenburg, P. S., & Kef, S. (2013). Attachment, intellectual disabilities and mental health: Research, assessment and

intervention. *Journal of Applied Research in Intellectual Disabilities*, *26*(1), 34-46. https://doi.org/10.1111/jar.12010

- Sinason, V. (1989). The psycholinguistics of discrimination. In B. Richards (Ed.) Crises of the Self: Further Essays on Psychoanalysis and Politics. (pp. 217-227) Free Association Books.
- Sinason, V. (1992). *Mental handicap and the human condition—New approaches from the Tavistock.* Free Association Books
- Sinclair, N. (2018). Transforming care: problems and possible solutions. *Tizard Learning Disability Review*, 23(1), 51-55. https://doi.org/10.1108/TLDR-10-2017-0040
- Skelly, A. (2020). Trauma exposure and the importance of attachment in people with intellectual disabilities. *Bulletin of the Faculty for People with Intellectual Disabilities*, 18(1), 15-19. https://doi.org/10.53841/bpsfpid.2020.18.1.15
- Spencer, N., Devereux, E., Wallace, A., Sundrum, R., Shenoy, M., Bacchus, C., & Logan, S. (2005). Disabling conditions and registration for child abuse and neglect: a population-based study. *Pediatrics*, *116*(3), 609-613. https://doi.org/10.1542/peds.2004-1882
- Storey, J., Collis, M. A., & Clegg, J. (2012). A psychodynamic interpretation of staff accounts of working with people who have learning disabilities and complex needs. *British Journal of Learning Disabilities*, 40(3), 229-235. https://doi.org/10.1111/j.1468-3156.2011.00697.x
- Sweeney, A., Filson, B., Kennedy, A., Collinson, L., & Gillard, S. (2018). A paradigm shift: relationships in trauma-informed mental health services. *BJPsych Advances*, 24(5), 319-333. https://doi.org/10.1192/bja.2018.29

Taylor, J., & Trout, S. (2013). Lessons from the front line: working with offenders with learning disability and personality disorder in a high secure therapeutic community. *Mental Health Review Journal*, 18(1), 44-52. https://doi.org/10.1108/13619321311306974

- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 1-10. https://doi.org/10.1186/1471-2288-8-45
- Torr, J. (2003). Personality disorder in intellectual disability. *Current Opinion in Psychiatry*, 16(5), 517-521.
- Truesdale, M., Brown, M., Taggart, L., Bradley, A., Paterson, D., Sirisena, C. & Karatzias, T. (2019). Trauma-informed care: A qualitative study exploring the views and experiences of professionals in specialist health services for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32(6), 1437-1445. https://doi.org/10.1111/jar.12634
- Tyrer, P., Casey, P., & Ferguson, B. (1991). Personality disorder in perspective. *The British Journal of Psychiatry*, *159*(4), 463-471. https://doi.org/10.1192/bjp.159.4.463
- Wigham, S., & Emerson, E. (2015). Trauma and life events in adults with intellectual disability. *Current Developmental Disorders Reports*, 2(2), 93-99. https://doi.org/10.1007/s40474-015-0041-y
- Wolfensberger, W. (1983). Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation*, 21(6), 234. https://doi.org/10.1352/1934-9556-49.6.435

- World Health Organization. (2022). *ICD-11: International classification of diseases* (11th revision). https://icd.who.int/
- Wright, K., Haigh, K., & McKeown, M. (2007). Reclaiming the humanity in personality disorder. *International Journal of Mental Health Nursing*, 16(4), 236-246. <u>https://doi.org/10.1111/j.1447-0349.2007.00480.x</u>
- Zenderland, L., & Trent, J. W. (1995). Inventing the Feeble Mind: A history of mental retardation in the United States. *Journal of American History*, 82(1), 235. https://doi.org/10.2307/2082002
- Zarotti, N., Hudson, C., Human, H. R., Muratori, G., & Fisher, P. (2022). 'It's working together with what you've got': Healthcare professionals' experiences of working with people with combined intellectual disability and personality disorder diagnoses. *Journal of Applied Research in Intellectual Disabilities*, 35(6), 1317-1326. https://doi.org/10.1111/jar.13020

Section B

Exploring staff experiences of psychodynamic trauma-informed care in complex intellectual

disability settings.

Word Count: 7999 (500)

Candidate number: CP 4817285/19

Abstract

Background: People with intellectual disabilities are at higher risk of experiencing trauma, adversity and having complex attachment needs. Consequently, they may be more likely to present with patterns of emotions, behaviours and relationships that could be labelled as 'personality disorder', which can be poorly understood by those caring for them. 'Trauma Informed Care (TIC) is receiving more emphasis in this domain of care, in which knowledge and skills related to trauma seek to foster sensitive, healing environments that are conducive to wellbeing for clients and staff alike.

Aims: To explore staff experiences of psychodynamic TIC training and to understand this in the context of their role and wider culture of care.

Design: Semi structured interviews were conducted with eight staff members who had taken part in psychodynamic TIC. Interpretative Phenomenological Analysis was conducted on the data.

Results: Four superordinate themes and 14 subthemes were derived from the analysis. Superordinate themes identified were: 'Enlightened is Empowered,' 'Emotional Impact of Learning', 'Moving the Wheels of Transforming Care' and 'Distress in the Role'. **Discussion:** Psychodynamic trauma informed teaching was greatly valued by participants. Profound realisations were described in which experiences in the present and in retrospect made more sense and the needs of clients were clearer to them. Participants described elevated skills in formulation and emotional regulation which had implications at the individual, team and organisational levels, ultimately benefitting client care. Significant trauma and adversity in the role was highlighted which begs consideration in terms of service planning regarding supervision, reflective practice and other support structures.

Introduction

People with intellectual disability (ID) are more vulnerable to experiencing trauma, abuses and maltreatment of any form across the lifespan (McNally et al., 2022; Murray & Osbourne, 2009; Spencer et al., 2005). Furthermore, systemic inequalities are evident across social, economic and health outcomes for people with ID (National Institute of Clinical Excellence, 2021; White et al., 2023). Recovery from trauma may be complicated by factors related to a person with ID's ability to process, communicate or address their trauma (Skelly, 2020). The convergence of risk factors related to trauma, adversity and developmental difficulties mean that people with ID may be more susceptive to presenting with patterns of behaviours, emotions or relationships that could be labelled as personality disorder (PD) (Pridding & Proctor, 2008). Many people in institutional care in the UK would be represented by this description, typically referred to as people with 'complex care needs' (Frankish, 2016b). The term PD can be used euphemistically and unhelpfully in this setting with *'a sigh roll of the eye that consigns the person to a waste bin'* (Anderson et al., 2020) in which their histories and difficulties are neither recognised nor understood.

The landscape of care for people with ID has been in a state of flux for many decades. Several iterations of political scrutiny and reform have been prompted since the 1970's, most often by scandal (Clifford et al., 2018). Repetitious cycles of opprobrium and reform in care services exposed a profound complacency toward the needs and rights of people with ID, each iteration promising (and likely aspiring) to be the harbinger of a new ethical era and culture (Clegg & Jones, 2014; Paterson, et al., 2013). Processes of deinstitutionalisation commenced in the 1980's and are still ongoing, with renewed impetus following the Winterbourne View scandal (BBC, 2011), which exposed institutional neglect and abuses of people with ID and/or autism (Hudson et al., 2021). A subsequent inquiry outlined failures in safeguarding practices, service regulation and care commissioning in which people with ID

and/or autism were detained in inappropriate and out of area placements (Flynn & Citarella, 2012). A national movement to restructure care and redress these failings ensued under 'Transforming Care' (TC) (Department of Health, 2012).

Winterbourne View eclipsed preceding scandals in its impact and reach, however, the TC agenda has been beset by challenges and has not reached its intended potential, due to an absence of infrastructure in the community to absorb the volume and complexity of service users in institutional care (Sinclair, 2018; Taylor, 2019). Despite progress achieved, concerns are still present regarding long admissions, restrictive practices, in addition to care environments that are not considered to be therapeutic, such that patterns of distress, restraint and seclusion are still common (Care Quality Commission, 2020; Ince et al., 2022; Mencap, 2014). It is incumbent on mental health services to continue to improve and evolve toward healthier systems of care and to arrest the iatrogenic impacts that are still occurring in the present day.

Trauma Informed Care (TIC)

TIC has been gaining momentum in the UK and internationally as an instrument of embedding meaningful and sustained reform in the delivery of care for people with ID (Keesler, 2014; Sweeney et al., 2016). TIC describes innovative attention and sensitivity to how traumatic stress is present in the here and now for service users, and ways in which professionals, services and organisations can create healing or harmful environments accordingly based their understanding and skills relating to trauma (Harris & Fallot, 2001; Wilson et al., 2017). Staff are essential stakeholders in effecting meaningful change in quality of care, and accordingly, further training has been outlined in TC recommendations as fundamental to improving services (Bubb, 2014). The expectation of staff to realise TIC must be considered alongside the demands already placed on this workforce, who are often poorly paid, work long hours, often have been provided with limited training and are at high risk of physical and emotional injury (Howard et al., 2009). It must also be acknowledged that there are high levels of developmental trauma in this workforce (Maunder et al., 2010). Whilst staff training is essential to establishing a TIC culture (Purtle, 2020), simultaneous organisational and managerial engagement is requisite in the success of this process (Menzies Lyth, 1960).

Trauma informed (TI) approaches are receiving more emphasis across healthcare services, however, the evidence base is in its infancy (Truesdale et. al, 2019). In non-ID settings, there is preliminary evidence that TI training is beneficial in terms of staff attitudes, knowledge and burnout, in addition to client wellbeing outcomes (Ewers et al., 2002; Purtle, 2020). In ID settings, TI training has been associated with reduced use of restrictive practices, behaviours that challenge and *pro re nata* medication use (Keesler & Isham, 2017). It has also demonstrated some benefits in terms of staff wellbeing outcomes, such as increased morale, empathy and sense of empowerment (Keesler, 2016), greater skills in self-reflection (Gregson & Delaney, 2021), in addition to greater confidence (Frankish, 2016a). The benefits observed in wellbeing may speak to the detrimental effects of retraumatising environments on staff, as dissonance between institutional practices and one's values is a driver of burnout (Sweeney et al., 2016). Drawing robust inferences from the collective results is undermined by the heterogeneity of the studies, lack of active control comparisons, small sample sizes and underpowered analysis across the board; therefore, findings must be interpreted with caution.

The role of a competent and insightful workforce in a culture that facilitates recovery is of particular significance in the realm of ID. People with ID who have experienced trauma rely more on systems around them for good quality of life (Keesler, 2014). Furthermore, professional caregivers often represent deeply important relationships to people with ID, who can rely on them to meet their attachment needs (Clegg & Lansdall-Welfare, 1995; Schuengel et al., 2013). This bears great significance in terms of the potency of the care

relationship as a conduit for transformative and healing relational experiences (Bollas, 1979) or conversely, re-enactments of traumatic relational experiences (Bloom & Farragher, 2013). Furthermore, addressing trauma in individual terms, such as with therapy, is not always straightforward for people with ID. Gatekeeping of mainstream services can present obstacles to therapy (Chaplin et al., 2009), in addition to diagnostic overshadowing, such that trauma is obfuscated by one's ID (Daveney et al, 2019). Challenges in communication and comprehension can also complicate engagement. It must also be acknowledged that for a significant number of people with ID, talking or thinking about trauma is too painful and destabilising to tolerate (Rye et al., 2021).

Rationale for attachment and psychodynamic principles in TIC

People with ID have been underserved until recent years in most therapeutic modalities, including psychodynamic psychotherapy (Benson, 2004; O'Driscoll, 2009). Preliminary evidence is promising in terms of efficacy of emotion and trauma focused psychotherapies (Hollins & Sinason, 2000; James & Stacey, 2013; Skelly et al., 2018), however, the dominant models of care in ID services are behavioural in orientation, particularly in terms of formulating and responding to behaviours that challenge (Dilworth et al., 2011). Positive behaviour support (PBS) has robust evidence base in supporting people with ID with behaviours that challenge and can be beneficial in improving quality of life (Heyvaert et al., 2012), however, behavioural approaches may not be appropriate for those whose behavioural presentation is mediated by trauma (McNally et a., 2021), and may in fact be retraumatising if the essential underlying need is missed (Kildahl et al., 2020).

Attachment theory encompasses a rich set of concepts which examine the complex interactive processes between child and caregivers in early life, which profoundly influence the child's development of their sense of self, the other, and skills in emotional regulation (Ainsworth et al., 1978; Bowlby, 1973; Heard, 1982). Insecure and disorganised attachment

styles are more prevalent in people with ID (Hamadi & Fletcher, 2021). In her work with this group, Frankish (2018) draws on Mahler's theories of attachment which posit that one's emotional development is arrested at a point which attachment needs are not met (Mahler, 1974). In ID services, the disparity between a person's chronological age and emotional maturity is often attributed to ID rather than unmet psychological needs. This can perpetuate a misattunement whereby the person with ID may act in ways to get unassuaged attachment needs met, or as an expression of distress related to trauma, which is misconstrued as behaviours that challenge related to ID. Experiences in care environments that foster a sense of emotionally safety in addition to providing the necessary 'missing ingredients' are essential to supporting emotional development (Shackleton, 2016).

Psychodynamic theory posits that early attachment and trauma shape development of personality, defence mechanisms and attributions of meaning to the actions and intentions of the self and others (Fonagy & Target, 2007: Malan & Parker, 1995). Unconscious defences such as splitting and projection are employed to protect one from intolerable psychic pain (Freud, 1941) which can manifest in care relationships to the detriment of service users and staff alike if not properly understood and managed (De Board, 2014; Slakter, 1987). Staff can experience shame, anxiety and guilt at the intense emotional countertransference reactions to their clients, rather than understand this as important information about the clients' inner worlds, (Casement, 1985; Kurtz & Jeffcote, 2011). Frankish (2018) observed that staff responding to distress in their clients may feel themselves distressed or angry, which may shift the focus to their own emotional safety, away from the service user. A recommendation put forth by her work to safeguard the health of teams, and enhance the care provided, was to build skills in self-reflection, recognising countertransference reactions and a psychological understanding of the challenges that arise in caring for traumatised individuals.

Caring for a Person with Personality Disorder and Intellectual Disability Training (CaPDID)

CaPDID was developed by a mental health ID service in the UK and imparts TI approaches for care staff who work with people with ID and a history of trauma. It developed from a need identified by repeated referrals from care providers in crisis, seeking support regarding people with complex and high risk emotional and behavioural difficulties. In this context, placements were at risk of breaking down, in addition to feelings of frustration, hopelessness and distress in the workforce.

The training is facilitated over three two-hourly sessions, typically in person. Referrals are open to anyone in a care team, however, managers are obliged to accompany members of their workforce to facilitate systemic application of the principles, and to support their team emotionally if needed. The theoretical underpinnings of CaPDID are predominantly attachment and psychodynamic as outline above, with notable influences from the work of Pat Frankish.

The syllabus elucidates and teaches skills related to the following:

- Defining and critically deconstructing 'personality disorder'
- Trauma; definition and impact across the lifespan
- Attachment Theory
- Transference and countertransference
- Splitting, of the self and of teams.
- Applying formulations to expressions of trauma in the present.

The Present Research

This study examines the experiences of third sector care staff who attended CaPDID training related to their work with people with ID and histories of trauma.

Rationale

TIC is a developing field in ID and complex care services and there is a dearth of research presently (Purtle, 2020). There does not appear to be any research examining psychodynamic TIC in this domain, much less staff's experience of this. By increasing the body of knowledge and developing this understanding further it is hoped that the resilience and competence of the workforce can be improved.

The different epistemic positions held by behavioural and psychodynamic practices mean that a move toward the latter would involve a cultural shift (Clegg, 1994), and therefore could be challenging to those engaging in it. Understanding this can help guide future endeavours in this regard for the betterment of TIC provision to this population.

Aims:

The aim of the proposed research is to explore the experiences of staff working in community settings, caring for people with ID and diagnoses of PD upon engaging with psychodynamic TI training; furthermore, exploring this within the context, culture and demands of their roles. It is hoped that this research deepens the empirical understanding of relationships between participants and the service users they support and how their experience of TI training has changed or influenced their roles.

Methodology

Design

This study utilised interpretative phenomenological analysis (IPA), (Smith et al., 2009) of eight individual semi-structured interviews. Given the exploratory nature of the research question with an expressed aim of accessing the lived experience of the participants, IPA was chosen as the appropriate means to do this, particularly as it copes well with emotional nuances of complex phenomena. IPA prioritises the experience of participants and the meaning they ascribe to their experiences through an active researcher employing a 'double hermeneutic approach', in which they attempt to makes sense of the participants making sense of their experiences (Smith and Osbourne, 2015). Engagement in self-reflexivity is therefore an essential process to mitigate undue influence of the researcher's biases and assumptions on the data (Larkin et al., 2006).

Expert by Experience Involvement

Individual consultations were held with three people who had completed the CaPDID training, in which the interview schedule was critiqued, in addition to an exploration to potential barriers to engagement from their perspectives. Two potential barriers to engagement were identified as fear of being judged by the researcher, in addition to worries they were being tested on the content of the training. Proposed adjustments were discussed in supervision and then implemented into the design. Changes were made to the interview questions accordingly, as were explicit statements that research participation was not an assessment of participants' knowledge. The researcher modelled humanistic principles in the interview to mitigate fears of judgement as much as possible (Rogers, 1951).

Recruitment

Participants were purposively sampled from CaPDID training cohorts whereby people who had completed the training were invited by the facilitators to opt in to be contacted by the researcher if they were interested in participating. Those who expressed interest were contacted by email inviting them to take part, in addition to providing an information sheet (see Appendix C).

Participants

The sample consisted of eight people working in a range of residential and supported living services for people with ID in the community. At least one service user living in the service where each participant worked had difficulties with emotional regulation and/or in

relationships with others which were thought to be related to histories of trauma. The sample size was deemed appropriate in relation to IPA conventions, in which smaller samples are preferable allowing for sufficient data saturation without undermining the homogeneity of the sample (Noon, 2018). Participants were eligible if they completed the CaPDID training and were interested and willing to participate.

Table 1

Demograph	ic Data
-----------	---------

Participant	Gender	Role	Years of experience
1	Female	Support Worker	17
2	Male	PBS Practitioner	12
3	Female	PBS Practitioner	17
4	Male	Manager	20+
5	Male	Support Worker	11
6	Female	Support Worker	12
7	Female	Manager	12
8	Female	Manager	6

Participant information will be presented sparingly to protect anonymity. Participants' ages ranged from early thirties to late fifties. Six participants were White British, one was Black African and one was of Asian ethnicity. Four participants engaged in training remotely due to contemporary covid restrictions and four completed it in person. Data collection occurred between two and 11 months after completion of training.

Procedure

Interviews were conducted on an online videoconferencing platform. Participants had signed consent forms (see Appendix D) electronically ahead of participating. Prior to engagement in the interview, a brief verbal descriptor of what to expect from engagement was offered, in addition to reminders about breaks and their right to withdraw. The interview schedule provided a structure to guide the discussion and prompts were used flexibly in relation to matters arising organically from the conversation.

Interview duration ranged between 46 and 93 minutes. Interviews were conducted between April 2021 and July 2023. Audio files and transcripts were stored on an encrypted memory stick from which identifying information was redacted. Transcription was conducted by a professional transcription company with reputable data protection policies. A confidentiality agreement was signed by the transcriber. Transcribed files were checked line-by-line by the researcher whilst listening back to the interviews to ensure quality and accuracy.

Analysis

Data was gathered and analysed in line with the protocol outlined by Smith et al. (2009). The first step involved an immersion in the raw data by repeated listening to interviews and reading of transcripts; then making initial annotations related to noteworthy descriptive, linguistic or conceptual content. Patterns in the comments led to the development of emergent themes, which were grouped together based on similarity and assigned a descriptive label, representing the themes for that participant. Patterns across cases were then observed from which the superordinate themes for the group were identified.

Quality Assurance

To ensure rigor in the analysis, the four principles of best practice for qualitative research outline by Yardley (2000) were observed. The researcher has had experience working in work environments similar to the participants, and as such, held biases that would influence her engagement with the data. A bracketing exercise was conducted ahead of data collection and analysis to draw out some of the influential assumptions and preconceptions that could interfere with analysis. A reflective diary was kept to aid holding an open and reflexive stance in relation to the content (see Appendix E). A randomly selected transcript was reviewed by the primary research supervisor to ensure congruence and validity in the themes (Appendix F). The themes were repeatedly compared to the transcripts to ensure they were grounded in the data.

Ethical Considerations

Ethical approval was granted by Salomons ethics committee (see Appendix G). Participants were informed ahead of involvement what it would involve in terms of their time, data, including recording, transcription and future dissemination and gave their consent to engaging.

Confidentiality and the limits of confidentiality were explored in writing and verbally. Detailed descriptors of the participant group were not reported to protect their anonymity. Potentially distressing aspects of the research were outlined ahead of the interview and participants were invited to take a break or withdraw if this occurred, in addition to a debrief space if required.

Self-Reflexive Statement

My interest in people with personality disorder, intellectual disability, staff experiences and psychodynamic concepts pre-exist my role within this research. My experience prior to clinical training was in a forensic medium-secure unit, in which I witnessed first-hand the discriminatory and retraumatising environments for people with complex relational histories and diagnoses of PD. Following this, I went to work in a group analytic Therapeutic Community for people with 'Severe and Dangerous Personality Disorder', in which my expanded knowledge of psychodynamic principles deepened my ability to conduct my role with compassion and skill, in addition to helping me understand the intense team dynamics that I had witnessed and inhabited for several years. Far from being an outsider to this field, I had adjacent experiences to the participants, and I would describe myself as having a passion for the area. This offered some advantages in terms of knowledge and experience, however, it also meant that I had years to develop implicit attitudes and sources of bias which could unconsciously influence my treatment of the data. My proximity to the data required close attention, therefore bracketing and reflective techniques as described above were employed,

in addition to regular discussions in supervision. It was important to me that my lens as researcher did not obfuscate or unduly influence the data, and that the results were a faithful representation of the participants' contributions.

Results

Four superordinate themes and 14 subthemes were derived from the analysis, which are

presented in Table 2:

Table 2

Superordinate Themes	Subthemes	Number of Participants contributing to theme
1) Enlightened is	'A lightbulb moment': Profound realisations	8
Empowered	'Understanding breeds empathy'	7
	'Seeing with clarity': Insight into the self and	7
	other	5
	'I take a step back': Reflection over reaction	7
	Greater skills and confidence	
2) Emotional Impact of	'Having knowledge makes you calmer'	7
Learning	'I connected with it': Personal Resonance	7
	Emotional Reactions to Learning	6
3) Moving the Wheels of	Creation and Industry	6
Transforming Care	Passionate Caregiving	7
-	'They just don't want to listen'	5
4) Distress in the role	'My lowest point ever': Traumatic events	5
-	Emotional Impact of the role	8
	'We are trained to switch off': Disconnected	8

Superordinate Themes, Themes and Source n

1) Enlightened is empowered

This superordinate theme captures distinct, but interconnected experiences in which the participants described a sense of illumination, which generated satisfaction in its own right, but also, that this enlightenment was a vehicle to better empathy, skills and wellbeing.

'A lightbulb moment'

This subtheme spoke to a sense of having had profound realisations, and relief that came from coming to understand the seemingly incomprehensible.

'it was a lightbulb moment for me' (P5)

This was in the context of many years of experience, which added to the sense of value and poignancy.

In all the years I've been a support worker... that training was important for me to do. Because I learnt a lot that I thought I knew, that I didn't know... It had so much information that you could use, well, you could just use it throughout your life really. I didn't realise how much if somebody had suffered trauma, the extent it could affect them. And the ways it could affect them.' (P1)

A resonant theme emerged in which long misunderstood or perplexing phenomena were resolved and given a sense of order.

'I've always really struggled with how people who face trauma can reject love and good experiences. I found that really hard and it was explained to me, and that really helped. If all you feel is pain in relationships, you want to protect yourself..., that's why you reject it before you become rejected.' (P3)

This understanding was also connected to a realisation that services as they are, do not comprehend the effects and expressions of trauma, and in doing so, can be harmful.

'We have people come to be supported by us... I don't think we're doing them a favour a lot of the time because our staff don't know this stuff... we're kind of adding to these people's traumas and their needs... I think that's for me why so many of the mental health placements tend to break down, and maybe why we're in such a crisis in society, because we don't really understand it all, and half the time we do just think it's a pill, it's a tablet, and it's not'. P3

The limitations of PBS in this context were spoken to by five of the participants, four of whom were PBS practitioners, particularly in the ways in which it can underserve this population.

'The unconscious nature of the splitting was significant learning, where I think previously...I didn't notice how unintentional or unconscious that behaviour could be. I maybe was looking at it a bit too functionally... when actually it might deeper and more psychological'. (P2)

'Understanding Breeds Empathy'

Building a context for and deeper understanding of the origins of what might present as 'PD' resonated vividly in the data as a conduit of empathy.

'Understanding breeds empathy... especially when you're dealing with behaviours that are really challenging and stressful.' (P2)

Elevated insight was also connected to a deeper sense of empathy for teams working with complex and traumatised individuals, and a sense once more that something was resolved internally in terms of understanding why they shut down.

'I've always been big on empathy... but I guess I have sometimes been a bit dismissive of staff in that... I understood a bit more how staff can feel useless.' (P3)

'Seeing with Clarity': Insight into the self and other

The imagery of the eye was prominent in this subtheme, in which trauma and its associates were unveiled. This sense of revelation was significant in terms of new perspectives and deeper understanding of the client.

Now when I see her, I... see it. And, I see what the need is... and I think that was a bit of an eye opener. (P7)

It also illustrated a sense that team dynamics, particularly in terms of splitting, were now possible to identify and observe, rather than be '*sucked in*' to.

'It was that real understanding of splitting, it, allows me... to really see with clarity when that type of behaviour is going on...it's a lot sharper... and it's been easier not attribute intent to those kinds of behaviours'. (P4)

A sense of 'blindness' in navigating this complex terrain prior to the training was connected to additional challenges in an already complex role.

'You go through these things, but you go through them blindly. You never put a name ... or a scholar's eye to it. You get that they're not ok in their core ... but you don't quite know why, and that's where the theory comes in. It's marrying the experiences I go through with knowledge... It's something you don't really [notice] and pay attention to, but now I do, because I've gone through that training, I am aware of what's happening around me. When it happens, I [notice]' P8

'I take a step back'

This subtheme spoke to elevated skills in reflection and invoking a formulation in upsetting or challenging events, rather than reacting to the manifest behaviour.

'I take a step back... Before I would've thought, oh my god, why can't I help [client] more?' (P6)

There was a greater sense of control associated with this.

'Before I would have thought, are you just trying to cause trouble? Where now, I actually thought, what made you say that? I think I would've been more offended before' (P1)

Greater skills and confidence

It appeared that having knowledge was experienced as having a fortifying, empowering effect. Skills in emotional regulation were valued, in terms of calming the self, but also how

this facilitated co-regulating with clients in crisis situations, which was expressed as an essential skill in enhancing safety.

'I did breathing techniques with him which helped him, but it also helped me to just feel a lot more calmer in a situation that really could have been quite dangerous'. P1 Skills in formulation were also prominently expressed as valued, in terms of reflecting on staff member's reactions, but also in terms of communicating a formulation with which to facilitate understanding and emotional containment of the team.

'The manager was a bit stressed out and... exasperated... throwing their arms around, and you can sense they're quite stressed and angry ... and it helps to kind of bring down those feelings of anger maybe... to contextualise a person's behaviour within their diagnosis and within the formulation... I feel more confident to convey that information and talk about that... and feel more able to get people on board too. (P2)

It appeared that having TIC training had a positive effect on opening communication, giving an overall sense of a workforce better equipped to speak about their experiences. The importance of having a language to speak to somewhat ineffable experiences was named as important.

'Since the training, it's an open narrative, especially in supervisions, reflective practice where we can discuss and people can air their views.' (P5)

2) Emotional impact of learning

This superordinate theme encompasses a variety of rich emotional experiences related to the TIC training, in terms of what it evoked, and how it protected participants from negative emotional experiences.

'Having more knowledge makes you calmer'

The power of knowledge as an emotional container was resonant in the data.

'Having more knowledge makes you calmer in a crisis.' (P1)

This was present in terms of buffering against the vicissitudes inherent to the work: *'To understand that the splitting, it's not personal ... you might be the nice person today, you might be bad tomorrow. It's not ok but, you can accept it because you*

know that's how it works, you know?' P6

Knowledge was also related to reduced distress, in terms of guilt and helplessness when a person in their care went into crisis, or diffusing one's sense of responsibility if a client harmed or endangered themselves.

'The bad days where things don't go right and going oh... I don't know what to do, it's worked before, why ain't it working now? It's like trying to fix something... and now understanding that sometimes you might be able to fix it but sometimes you might not and that's ok and that it's not anything you've done as a person.' (P5)

This had the added effect of easing negative cycles of blame and reproach toward the self and other:

'Now when I'm on shift, it's more about thinking what I've learned than going in thinking, I can't do this, you know? I can't support you. Why can't I, why are you not letting me support you?' (P1)

This containment allowed for a greater depth of tolerance toward clients:

'I look at her with a different eye. I think I tolerate her more.' (P8)

It also appeared to translate to teams in which there was improved conflict and cohesion.

'The relationship [between] staff has gotten much better as well...because they're not challenging [or] hating on each other.' P7

This was also related to a protective effect on staff burnout, which was deemed a significant benefit to service users, giving the overall sense of a healthier ecosystem of care.

'Now we've got some very strong staff teams, and you're always gonna get turnover because it's very complex... This has been very low turnover compared to other complex services, that's a really good sign. Ultimately, it's life changing for some of those individuals...it's also about the kind of empowerment of staff.' (P4)

Personal Resonance

The content of the training resonated with participants in ways that went beyond professional interest and connected with their own histories, relationships and difficulties. The fact that they themselves are traumatised appeared to be a novel understanding for several participants, in addition to a realisation that their work could trigger deep seated anxieties.

'My dad had a breakdown, my mum had left home so it was just me... I think that sometimes comes back to me and that feeling of, thinking, there's no one. Who's gonna help me at the end of the day? And staff, it's who's gonna help them?' (P3)

This insight raised curiosity about unseen trauma in the workforce, and unconscious drivers to do the caring role.

'Some of us do this work because I think it resonates with us all... particularly those of us in caring professions. I wonder if there's a connection there?... I never wanted to be in care, never. I remember thinking I can't stay here long and I've been here... this is the 17th year.' (P3)

Emotional Reactions to Learning

It was apparent that engagement with this learning was emotionally charged at times and the participants were moved by the content and discussion.

'There was, there was once point where I was a bit emotionally overloaded.' (P1)

A sadness and anger emerged in relation to the realisations of what their clients experienced in terms of abuse or neglect.

'Mum and dad are supposed to protect you... It was quite sad really the fact that people don't have that in their life.' (P6)

Guilt was also expressed as a reaction to appraising themselves in the past with a new perspective, in which questions arose regarding their past practices.

'I had a lot of questions as to whether I've handled stuff the right way, maybe some guilt.' (P8)

There were also prominent hopeful emotional reactions in relation to being better equipped to influence positive change and a confidence about how to move forward.

'I felt quite enlightened and enthusiastic I suppose, kind of ambitious about how to make sense of it and transform it into... changes.' (P2)

This sense of ambition also arose with prominent imagery related to hunger and nourishment.

'I'm not sure what the right word is, but I'm greedy. I want more and more.' (P3)

3) Moving the Wheels of Transforming Care

Themes of industry, creation, and energy were prominent across the dataset, which evoked a sense that the cogs of the machinery of TC were exposed. A visceral sense of effort and push toward progress was evident, which manifested differently in relation to the professions of the participants.

'We're looking at trauma and attachment-based approaches more and more... We've talked about how we could take some of that learning... and how we can improve our practice and our offer across the organisation.' (P4)

This ambition was also apparent at the microlevel in terms of a restless urge to evolve and improve care at the individual or team level.

'You need to talk, you need to discuss but you need to be positive and you need to come up with ideas and solutions.' (P3)

Passionate Caregiving

A pattern of passionate, caring attitudes were present in the dataset, such that ethical clientcentred care was vividly represented.

'Seeing quality of life changes and improvements, it's the be all and end all really for me.' (P2)

The moral grounding of the work resonated in terms of a passionate interest in client welfare, in addition to a sincere sense of care, and at times, affection:

'You kind of have to take the role of family... they're not here, but if you need me, I'm here.' (P6)

Their work was experienced as rewarding and meaningful for participants; there was cohesion regarding a profound satisfaction experienced in influencing positive change in peoples' lives, but also that the work was enriching in its own right.

'You learn a lot doing this kind of role. You learn about yourself.' (P1)

Apathy and Inertia

Coping with obstacles and impasses resonated throughout the data, particularly in terms of stalemates with teams in which communication had broken down, and the rage and sadness that came with it.

'My low points are... when you're working with a team and they just don't want to listen.' (P3)

This was related to a burnt out and demoralised workforce, for whom a wall had been erected from exhaustion:

'everybody's just tired and not wanting to be there'. (P8)

A sense of inertia was also related to enervated social service and community resources, which gave a stranded quality to the participants' experience.

'If you've worked in social care, you will have seen these people say, we're gonna solve all these problems, we're gonna get people out of hospital. But there's still...systemic problems... the frustration is that those community-based resources and options you need, still don't exist. (P4)

4) Distress in the role

'My lowest point ever': Traumatic events

The ubiquity of adversity faced by the participants was sobering to observe, such that calamity and hardship were commonly experienced.

'Major self-harm. We deal with a lot of blood. We deal with drugs. We deal with going on to a bridge and wanting to jump off. Ligatures, overdose, I mean you name it, everything. Abuse to staff. Physical and verbal. It's deep.' (P8)

A fragile sense of safety was also prominent, such that a state of vigilance was palpable. *'We would think he's ok, and then the next minute he's not and you're literally running after him tryna stop him from harming himself... it can all change on the spot.* '(P1)

Distress and outrage also emerged in relation to observing institutional neglect and abuse. Although some were from years past, there was a fresh quality to the emotion evoked.

'When go into places and you realise what's happening...' (P3) Some of the language evoked visceral imagery, in which once more, memories had a vital and recent quality, illustrating the extent to which the role could be horrifying. 'The worst was my first encounter with the client who tied a ligature around her neck and seeing her turn purple. And I couldn't do anything... but you see she's sinking. That was probably my lowest point ever. It was horrible... horrible.' (P8)

Emotional impact

The emotional complexity and nuances the participants felt within their work were striking and expansive. It appeared that past clients lived on in the minds of participants. This was in relation to profound affection and subsequent grief when a client or professional 'moved on'.

'You get attached to people... I had one resident I was with from the start and she left last year. When she left, that was quite difficult. I still think about her... I hope she's ok'. (P6)

Anger was also resonant, in relation to experiences of abuse from clients, but more typically regarding colleagues. Adversarial and combative interactions with colleagues appeared to be among the most stressful aspect of the role.

'It's the shit you get... especially when you're talking to the people that are getting investigated.' (P7)

The presence of fear in the data was most often related dread that a client would seriously injure themselves, however, fear of being physically harmed oneself was notably absent considering the ubiquity of the risk in the role. The clients were at times represented as quite powerful relationally, in ways that evoked a sense of being powerless and trapped.

'She got too fond of me. She's told me the moment I'm not coming back, she will... that's it. It really became, – I wanna use the word relationship but... it definitely was bad.' (P8)

The perceived relentlessness of the role emerged in terms of a frustration:

'The frustration really in social care is... the demands just go up and up and up and the resource does not necessarily keep pace with the demands.' (P4)

and an emptiness, a sense that there was no more to give.

"when I'm at that point where I'm drained, I'll just go through the motions" (P8) A disillusionment punctuated the data, along with a stoicism which evoked a sense that this was a cohort inured to disappointment and broken promises.

'When we had the Winterbourne View thing, everyone was like this is a game changer... Transforming care hasn't achieved what it set out to achieve really. I see people all the time that shouldn't be in hospital...for no other reason other than the fact that they've got autism and complex behaviours. So that's the frustration.' (P4)

"We are trained to switch off"

A thread of disconnection wove throughout the data, manifesting in a variety of ways. It was named as an explicit and conscious coping mechanism. It was acknowledged unprompted that this work could be intolerable in several interviews.

'I have this ability to shut it out. I put it in a box and I push it away... even shelve it would be the wrong term... I dig a deep pit and I bury it... And I crack on.' (P8) The denial of difficult emotions was named as problematic:

'That machismo thing of "yeah it's difficult and all that but I just get on with it"... That's a bit of a blocker... you still get...people seeing it as a sense of weakness if they're not coping. And that absolutely shouldn't be because we're working with very difficult stuff day to day. (P4)

Fascinatingly and somewhat ironically, this participant re-enacted this by avoiding answering questions regarding the emotional impact of the work on himself, swerving to answers about organisational planning or to staff. This pattern of pivoting away from the self was more present in male interviews. There was a brittle quality to this coping mechanism:

'[voice cracking] They say to me...nothing phases you, does it? You just hold it together all the time.' (P1)

There were many inadvertent or potentially unconscious examples of disconnection in the data, such a disconnection from the primary task of care:

"What's rewarding is if things work out in my favour... and I've made a profit"

(Participant identifier withheld).

In addition to a dismissive responses to colleagues:

"staff coming to me and ranting about something... they're definitely using methods and trying to not get upset about things easily." (P7)

Bland and sterile language to describe visceral events was also prominent throughout, which had a mild anesthetic effect.

"She's a prolific self-harmer or what have you" (P5)

There was a pervasive use of unironic understatement, which gave much of the data a shrouded quality, which felt as though it concealed simultaneously as it revealed.

'What I don't like is when they're not well. Because that's not nice to see. '(P6) The cumulative effect of this avoidance gave the impression of a wariness of wading toward or making content with disturbing or overwhelming emotions.

Discussion

This study sought to explore the experiences of staff of engaging in psychodynamically informed TIC training related to their roles caring for people with ID with histories of trauma, and to understand this within the culture and demands of their roles. The findings of this exploration yielded four superordinate themes which will be considered in the context of the research question and existing literature.

Key findings

Engaging in CaPDID appeared to be a valued and profound experience for the participants. Epiphany is defined as a transformational experience in which a fundamental meaning structures are reorganised (McDonald, 2008). 'Illuminative epiphanies' can bring with them a revision of one's past experiences and a sense of shift in identity (Denzin, 1990). This experience of illumination and something fundamental shifting within and without was present in the experiences of many of the participants. The imagery of the eye was recurrent to the extent that it seemed as though some of the participants felt they were given a second sight to what was happening in the present and in retrospect, a helpful result of which was that they were less reactive to clients and colleagues. Stepping back also seemed to evoke a sense of '*I see what the need is*', which is promising considering the aforementioned work and recommendations set forth by Frankish (2018) and Mahler (1974) in seeing beyond behaviours that challenge to the essential underlying need.

A sense of resolution and satisfaction was also prominent in the data, such that it seemed as though a long unassuaged need was met. This was reinforced by imagery related to hunger, want and satisfaction, in which basic needs of the infant were evoked. In other literature exploring the experiences of staff working with people with ID and PD diagnoses, the want of knowledge, and feelings of insecurity and vulnerability it conjured were prominent themes, suggesting that this phenomenon may be widespread (Dalgarno & Riordan, 2014; Lee & Kiemle, 2015; Storey et al., 2012).

Greater knowledge appeared to lead to a concatenation of enabling, empowering, insights and skills, giving a greater sense of control in a chaotic and sometimes overwhelming setting. The participants' experiences of emotional fortification was fascinating and appeared to have ripples within the self, the client and the team. Bion (1961) posited that distressing experiences remain fragmented within one's psyche in the absence of

language or a container within which they could be explored and metabolised. Obholzer (1986) extended this to organisations, within which effective containment facilitates reduction of anxiety, enables thinking, acknowledgment of and management of problems, which may offer a helpful framework to understanding the observed effects. Engagement in the training also elicited painful feelings in the participants, such as feeling guilty, 'overloaded' and connecting with the tragedy endemic in the lives of their clients. Several participants connected to their own trauma in this context also. For some it was a conduit to insight that they themselves are traumatised, which is valuable learning considering potential for unconscious re-enacting or re-experiencing trauma for both parties of the caring dyad.

There was a hopefulness and enthusiasm in some of the reactions to the TIC learning which felt part of a larger context of renewal and evolution within ID services, however, this was not uncomplicated. There was a fascinating discourse and tension between hope and cynicism, between change and stagnancy within these themes, such that the participants appeared to be realising the aspirations of TC whilst disillusioned with it. The work appeared to have deep meaning across the board for participants, such that there was an intrinsic driver toward change and growth, rather than extrinsic drivers. The passion, verve and sense of meaningfulness in the role has not been highlighted in other research in this domain, and as such bears acknowledgment. That said, a fatigue was also present, and a frustration at the impotence of ambition and vigour against overwhelming apathy in teams, austerity, or a dearth of material resources. The push and pull of these opposing forces gave the sense of a liminal space wherein both forces existed simultaneously, in which standing still felt like moving backwards. Most of the participants had worked before and through the Winterbourne scandal, which may speak to this sense of urgency to move forward and break unhelpful cycles.

The presence of adversity and ordeal in the role was spoken to directly by most participants. The aggregation of their traumatic experiences was harrowing to read and reread in the composition of this research. Language evoking calamitous events were sometimes raised in an incongruously offhand or affable manner, to which there was a disconnected quality. Conversely, other recollections had a vivid recency to them. The duality of intrusion and detachment are indicative of unprocessed trauma responses (Nijenhuis & van der Hart, 1999), which speaks to the distress that people in this field are carrying.

The complexity and range of the emotional impact of the work was notable. The word love has an unspeakable quality to it in care settings (Arman & Rehnsfeldt, 2006) and can be perceived as unprofessional or even risky, despite being a relatively common experience in caring relationships (Stickley & Freshwater, 2002); it stood upspoken in the background of many conversations. Fascinatingly, distressing and traumatic aspects of the role also had a shrouded quality linguistically. This begs consideration of how much of the emotional experience of this workforce has an alienated or shameful quality to it, which Huet (2011) also noted on in her exploration of staff experience in this field, which may speak to a wider phenomenon in this regard.

It appeared that cutting off from the emotional intensity demanded of the work was a common way in which people survived it, considering the variety and frequency with which it arose. Machismo, minimisation and an outward disconnection from internal feelings have been spoken to by other explorations of experiences of this workforce (Huet, 2011; Lee & Kiemle, 2015; Storey et al., 2012) which points to a cultural rather than idiographic phenomenon. Foster (2001) argued that caring for very complex clients places a paradoxical expectation on staff to be in touch with clients' emotions and their own, placing them perilously close to disturbing feelings; the internal conflict of which necessitates splitting off parts of awareness to cope. An essential task is in the reintegration of these experiences,

which appears to have occurred to some extent in the training, but requires ongoing reflective and supervisory spaces. Many of the participants spoke to the essential nature of reflective spaces in their role, and three explicitly referenced taking part in the research as an opportunity for reflection. This bears careful consideration when one considers the landscape of care provision as it stands in which supervision and support can be limited (Jackson, 2014) despite being essential to building resilient and thoughtful teams. The positive impact of CaPDID in facilitating reflective team working and the protective effect it had on team health and quality of care is a promising reflection.

The outlier

One of the participants diverged from the rest of the sample in several ways. They held disinterest without expressing objection to CaPDID concepts and as such had noticed no difference to their working or thinking. They referred to clients as 'customers' and had a uniquely transactional, corporate way of describing their role and goals. They had previous experience on the frontline, but attended CaPDID in their capacity as manager accompanying staff because they 'had to', which begs curiosity as to the extent the values of the training would be embedded in this service. To acknowledge this is not intended as opprobrium; holding complexity and contradictions in the data and integrating the prism of their experience into this narrative is important as they likely speak to others' experiences too. The concept of the anti-group was called to mind (Nitsun, 2014), in which disruptive group processes express fear and hostility that can potentially undermine therapeutic function. Recognising and addressing the drivers of the anti-group processes have therapeutic and constructive potential, though it is beyond the scope of this paper to explore it further.

Limitations

Despite quality assurance measures, it is likely that the researcher's biases influenced the data collection, analysis and interpretation considering her background in a similar area. The

group was somewhat heterogenous and as such the findings likely lack nuances that may have been perceived in a more homogenous sample. It is not possible to determine causality in the reported effects, however, the findings reflect and expand on the themes from other studies on TIC in this area (Ewers et al., 2002; Gregson & Delaney, 2021; Keesler, 2016; Purtle, 2020) which although still tentative, lends them more credibility. It must also be acknowledged that those who volunteered to participate may represent the most positively affected, which may not be representative of broader experiences. It is a defining limitation that the 'outlier's' experience could not be understood with more depth, as it would provide invaluable insights into potential barriers to engagement.

Clinical Implications

This research is of a small and exploratory nature and as such, one cannot make robust inferences from the data, however, it has legitimate clinical significance for several reasons. It is a strength of the research that it was composed of an experienced sample, and as such are arguably more discerning. There was an effusive quality to the expressed value and utility of this learning, particularly in terms of improved emotional wellbeing for the individual and the team, thus positively impacting care. The power of TIC to ripple throughout a care system is promising considering that the participants and creators of CaPDID are consciously trying to break cycles of 'corrupted cultures', in which clients and staff alike are neglected and dehumanised (Clifford et al., 2018). The findings demonstrate that psychodynamic principles appear to be accessible and valued in this context, and that it offered something that PBS was missing. The recurrence of this theme from PBS practitioners is significant. The high levels of trauma in the role the underline the importance of supervision, reflective and support structures for staff members.

Research Implications

As far as can be determined, this is novel research in an area undergoing seismic shifts that has been sorely neglected in the literature; as such, more research is needed. Larger scale quantitative research examining effects over time would be valuable. So too would research exploring men's experiences, particularly with the recurrence of 'machismo' themes in present and other literature. This is a diverse area of employment ethnically, there is no research examining the nuances of black and ethnic minority peoples' experience, insights into which would be valuable. Exploring people with ID's experiences of TIC would be important in progressing this area further.

Conclusion:

Psychodynamic TIC appeared to be valued, evocative, empowering to the staff in the context of their complex and demanding roles. Participants described a nexus of positive impact from their learning in terms of satisfaction, improved skills in formulation, emotional regulation and empathy which had impact at an intrinsic level, within teams, organisations and crucially, in the care of the individual. This is poignant when considered against the significant trauma and adversity they faced in their roles and the deep commitment to being part of a meaningful reform of care. One participant's experience is not described by the above, however, it is beyond the scope of this research to offer a robust understanding of this. It is imperative to continue to shine a light on this promising area of TIC, to build an evidence base which can be used to guide continued growth and meaningful reform in the care of people with ID.

References

- Ainsworth, M. D. S., Blehar, M. C., Waters, E., & Wall, S. N. (2015). Patterns of attachment: A psychological study of the strange situation.(Classic Ed.) Psychology press. (Original work published 1978) <u>https://doi.org/10.4324/9780203758045</u>
- Anderson, J., Pickard, M., & Rye, E. (2020). *The CaPDID training manual: A traumainformed approach to caring for people with a personality disorder and an intellectual disability.* Pavilion Publishing.
- Arman, M., Rehnsfeldt A. (2006) The presence of love in ethical caring. *Nurses Forum*, 41(1), 4–12. https://doi.org/10.1111/j.1744-6198.2006.00031.x
- BBC (2011). Panorama Undercover care the abuse exposed [TV Documentary]. https://www.bbc.co.uk/programmes/b011pwt6
- Benson, B. A. (2004). Psychological interventions for people with intellectual disability and mental health problems. *Current Opinion in Psychiatry*, 17(5), 353-357. https://doi.org/10.1097/01.yco.0000139969.14695.dc

Bion, W. R. (1961). Experiences in groups: And other papers. Tavistock.

- Bloom, S. L., & Farragher, B. (2013). Restoring sanctuary: A new operating system for trauma-informed systems of care. Oxford University Press.
- Bollas, C. (1979). The transformational object. *The International Journal of Psycho analysis*, 60(1), 97-107.

Bowlby, J. (1973) Attachment and Loss. Vol 2: Separation: Anxiety and Grief. Basic Books.

Bubb, S. (2014). Winterbourne View – time for change: Transforming the commissioning of services for people with learning disabilities and/or autism. UK: Transforming Care and Commissioning Steering Group. https://www.england.nhs.uk/wpcontent/uploads/2014/11/transforming-commissioning-services.pdf Care Quality Commission, (2020). *Out of Sight – Who Cares? Restraint, segregation and seclusion review.* <u>https://www.cqc.org.uk/publications/themed-work/rssreview</u>

Casement, P. (1985). On Learning From the Patient. Routledge.

- Chaplin, E., O'Hara, J., Holt, G., & Bouras, N. (2009). Mental health services for people with intellectual disability: challenges to care delivery. *British Journal of Learning Disabilities*, 37(2), 157–164. https://doi.org/10.1111/j.1468-3156.2008.00540.x
- Clegg, J. A. (1994). Epistemology and learning disabilities: invited commentary on Hastings and Remington. *British Journal of Clinical Psychology*, 33(4), 439-444. https://doi.org/10.1111/j.2044-8260.1994.tb01141.x
- Clegg, J. A., & Lansdall-Welfare, R. (1995). Attachment and learning disability: a theoretical review informing three clinical interventions. *Journal of Intellectual Disability Research*, 39(4), 295-305. https://doi.org/10.1111/j.1365-2788.1995.tb00521.x
- Clegg, J., & Jones, J. (2014). Intellectual disabilities: Expanding the field of vision. In J. Z Sadler, C.W. Van Staden, K.W. Fulford (Eds.) *The Oxford Handbook of Psychiatric Ethics, Volume 1* (pp. 147–160).

https://doi.org/10.1093/oxfordhb/9780198732365.013.18

- Clifford, A., Standen, P. J., & Jones, J. (2018). "I don't want to take any risks even if it's gonna mean this service-user is gonna be happier": A thematic analysis of community support staff perspectives on delivering Transforming Care. *Journal of Applied Research in Intellectual Disabilities*, *31*(6), 1209-1218. https://doi.org/10.1111/jar.12495
- Dalgarno, M. F., & Riordan, S. A. (2014). Forensic learning disability nursing: what's it really like? *Journal of Intellectual Disabilities and Offending Behaviour*, 5(4), 167-177. <u>https://doi.org/10.1108/JIDOB-11-2014-0017</u>

- Daveney, J., Hassiotis, A., Katona, C., Matcham, F., & Sen, P. (2019). Ascertainment and prevalence of post-traumatic stress disorder (PTSD) in people with intellectual disabilities. *Journal of Mental Health Research in Intellectual Disabilities*, *12*(3-4), 211-233. https://doi.org/10.1080/19315864.2019.1637979
- De Board, R. (2014). The psychoanalysis of organizations: A psychoanalytic approach to behaviour in groups and organizations. Routledge.

Denzin, N. (1990) Interpretive Interactionism. Sage Publications.

Department of Health (2012). Transforming care: A national response to Winterbourne View Hospital. Department of Health.

https://assets.publishing.service.gov.uk/media/5a7b91f7ed915d13110601c3/finalreport.pdf

- Dilworth, J. A., Phillips, N., & Rose, J. (2011). Factors relating to staff attributions of control over challenging behaviour. *Journal of Applied Research in Intellectual Disabilities*, 24(1), 29-38. https://doi.org/10.1111/j.1468-3148.2010.00570.x
- Ewers, P., Bradshaw, T., McGovern, J., & Ewers, B. (2002). Does training in psychosocial interventions reduce burnout rates in forensic nurses? *Journal of Advanced Nursing*, 37(5), 470-476. https://doi.org/10.1046/j.1365-2648.2002.02115.x
- Flynn, M., & Citarella, V. (2012). Winterbourne View Hospital: a serious case review. South Gloucestershire Safeguarding Adults Board. https://www.ruh.nhs.uk/about/trustboard/2012_09/documents/12_appendix_2.pdf
- Fonagy, P., & Target, M. (1997). Attachment and reflective function: Their role in selforganization. *Development and Psychopathology*, 9(4), 679-700. https://doi.org/10.1017/s0954579497001399
- Foster, A. (2001). The duty to care and the need to split. *Journal of Social Work Practice*, 15(1), 81-90. https://doi.org/10.1080/02650530120042028

- Frankish, P. (2016a). Evaluating the Impact of Providing Training for Direct Care Staff in how to Provide an Emotionally Nurturing Environment for People with Intellectual Disability and Complex Needs. *Journal of Intellectual Disability - Diagnosis and Treatment*, 4(1), 41–43. https://doi.org/10.6000/2292-2598.2016.04.01.5
- Frankish, P. (2016b). Psychotherapy and attachment dynamics in people with intellectual disabilities: a personal view. In H. K. Fletcher, A. Flood, D. J. Hare (Eds) Attachment in Intellectual and Developmental Disability: A Clinician's Guide to Practice and Research, (pp. 130-150). John Wiley and Sons.

https://doi.org/10.1002/9781118938119.ch7

- Frankish, P. (2018). Disability psychotherapy: An innovative approach to trauma-informed care. Routledge. https://doi.org/10.4324/9780429473784
- Freud, S. (1941), Splitting of the ego in the defensive process, International Journal of Psychoanalysis, 22, 65–68. (Original work published 1938).
- Gregson, N., & Delaney, C. (2021). Drawing in not encouraging away: systemic team formulation to support the trauma-informed care of a lady with intellectual disabilities, in the context of COVID-19. *Advances in Mental Health and Intellectual Disabilities*, 15(5), 171-184. https://doi.org/10.1108/AMHID-12-2020-0032
- Hamadi, L., & Fletcher, H. K. (2021). Are people with an intellectual disability at increased risk of attachment difficulties? A critical review. *Journal of Intellectual Disabilities*, 25(1), 114-130. https://doi.org/10.1177/17446295198647
- Harris, M. E., & Fallot, R. D. (2001). Using trauma theory to design service systems. New Directions for Mental Health Services. Jossey-Bass.
- Heard D. (1982) Family systems and the attachment dynamic. *Journal of Family Therapy*, 4(2), 99-116. <u>https://doi.org/10.1046/j..1982.00580.x</u>

Heyvaert, M., Maes, B., Van Den Noortgate, W., Kuppens, S., & Onghena, P. (2012). A multilevel meta-analysis of single-case and small-n research on interventions for reducing challenging behavior in persons with intellectual disabilities. *Research in Developmental Disabilities*, 33(2), 766-780.

https://doi.org/10.1016/j.ridd.2011.10.010.

Hollins, S., & Sinason, V. (2000). Psychotherapy, learning disabilities and trauma: new perspectives. *The British Journal of Psychiatry*, 176(1), 32-36. https://doi.org/10.1192/bjp.176.1.32

- Howard, R., Rose, J., & Levenson, V. (2009). The psychological impact of violence on staff working with adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22(6), 538–548. https://doi.org/10.1111/j.1468-3148.2009.00496.x
- Hudson, N., House, R., Robson, N., & Rayner-Smith, K. (2021). 'It's a good thing we're doing, we just need to be better at it'. Forensic intellectual disability nursing experiences of Transforming Care: A multi-perspectival interpretive phenomenological analysis. *Journal of Applied Research in Intellectual Disabilities*, *34*(4), 1066-1075. https://doi.org/10.1111/jar.12855
- Huet, V. (2011). Art therapy-based organisational consultancy: A session at Tate Britain. *International Journal of Art Therapy*, 16(1), 3-13. https://doi.org/10.1080/17454832.2011.575382
- Ince, R., Glasby, J., Miller, R., & Glasby, A. M. (2022). 'Why are we stuck in hospital?' Understanding delayed hospital discharges for people with learning disabilities and/or autistic people in long-stay hospitals in the UK. *Health & Social Care in the Community*, 30(6) https://doi.org/10.1111/hsc.13964

Jackson, W. (2014). Developing a values evidence-based clinical supervision model within a forensic intellectual disability service. *Journal of Intellectual Disabilities & Offending Behaviour*, 5(1), 14–23. https://doi.org/10.1108/JIDOB-09-2013-0020

- James, C., & M. Stacey, J. (2013). The effectiveness of psychodynamic interventions for people with learning disabilities: a systematic review. *Tizard Learning Disability Review*, 19(1), 17-24. https://doi.org/10.1108/TLDR-10-2012-0009
- Keesler, J. M. (2014). A Call for the Integration of Trauma-Informed Care Among
 Intellectual and Developmental Disability Organizations. *Journal of Policy and Practice in Intellectual Disabilities*, 11(1), 34 42. https://doi.org/10.1111/jppi.12071
- Keesler, J. M. (2016). Trauma-informed day services for individuals with intellectual/developmental disabilities: Exploring staff understanding and perception within an innovative programme. *Journal of Applied Research in Intellectual Disabilities*, 29(5), 481-492. https://doi.org/10.1111/jar.12197
- Keesler, J. M., & Isham, C. (2017). Trauma-Informed Day Services: An Initial Conceptualization and Preliminary Assessment. *Journal of Policy and Practice in Intellectual Disabilities*, 14(2), 164–175. https://doi.org/10.1111/jppi.12206
- Kildahl, A. N., Helverschou, S. B., Bakken, T. L., & Oddli, H. W. (2020). "If we do not look for it, we do not see it": Clinicians' experiences and understanding of identifying post-traumatic stress disorder in adults with autism and intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *33*(5), 1119 1132. https://doi.org/10.1111/jar.12734
- Kurtz, A., & Jeffcote, N. (2011). 'Everything contradicts in your mind': A qualitative study of experiences of forensic mental health staff in two contrasting services. *Criminal Behaviour and Mental Health*, 21(4), 245-258. <u>https://doi.org/10.1002/cbm.796</u>

- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3(2), 102-120. https://doi.org/10.1191/1478088706qp062oa
- Lee, A., & Kiemle, G. (2015). 'It's One of the Hardest Jobs in the World': The experience and understanding of qualified nurses who work with individuals diagnosed with both learning disability and personality disorder. *Journal of Applied Research in Intellectual Disabilities*, 28(3), 238-248. https://doi.org/10.1111/jar.12125
- Mahler, M. S. (1974). Symbiosis and individuation: The psychological birth of the human infant. *The Psychoanalytic Study of the Child*, 29(1), 89-106.
 https://doi.org/10.1080/00797308.1974.11822615
- Malan, D., & Parker, L. (1995). Individual psychotherapy and the science of psychodynamics. CRC Press. https://doi.org/10.1201/b13307
- Maunder, R. G., Peladeau, N., Savage, D., & Lancee, W. J. (2010). The prevalence of childhood adversity among healthcare workers and its relationship to adult life events, distress and impairment. *Child Abuse & Neglect*, 34(2), 114-123. https://doi.org/10.1016/j.chiabu.2009.04.008
- McDonald, M. G. (2008). The nature of epiphanic experience. *Journal of Humanistic Psychology*, 48(1), 89-115. https://doi.org/10.1177/00221678073118
- McNally, P., Taggart, L., & Shevlin, M. (2021). Trauma experiences of people with an intellectual disability and their implications: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, 34(4), 927-949.

https://doi.org/10.1111/jar.12872

McNally, P., Irvine, M., Taggart, L., Shevlin, M., & Keesler, J. (2022). Exploring the knowledge base of trauma and trauma informed care of staff working in community residential accommodation for adults with an intellectual disability. *Journal of*

Applied Research in Intellectual Disabilities 35(5), 1162-1173.

https://doi.org/10.1111/jar.13002

- Mencap in collaboration with the Challenging Behaviour Foundation. (2014). *Winterbourne View: The Scandal Continues*. <u>https://www.mencap.org.uk/sites/default/files/2016-</u> 08/Winterbourne View the scandal continues 0.pdf
- Menzies Lyth, I. (1960). 'Social systems as a defence against anxiety: an empirical study of the nursing service of a general hospital'. In E. Trist & H. Murray (Eds.) (1990). The Social Engagement of Social Science, Volume 1: The Socio-Psychological Perspective. Free Association Books.
- Murray, M., & Osborne, C. (2009). Safeguarding disabled children: Practice guidance.
 Department for Children, Schools and Families.
 <u>https://assets.publishing.service.gov.uk/media/5a7b27da40f0b66a2fc05897/00374-</u>2009DOM-EN.pdf
- National Institute for Clinical Excellence. (2021) People with a Learning Disability. *NICE Impact.* https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-useof-nice-guidance/impact-of-our-guidance/nice-impact-people-with-a-learningdisability
- Nijenhuis, E. R. S., & van der Hart, O. (1999). Forgetting and reexperiencing trauma: From anesthesia to pain. In J. Goodwin & R. Attias (Eds.), *Splintered Reflections: Images* of the Body in Trauma (pp. 39–65). Basic Books/Hachette Book Group.
- Nitsun, M. (2014). *The anti-group: Destructive forces in the group and their creative potential*. Routledge. <u>https://doi.org/10.4324/9781315745510</u>

- Noon, E. J. (2018). Interpretive phenomenological analysis: An appropriate methodology for educational research. *Journal of Perspectives in Applied Academic Practice*, 6(1). https://doi.org/10.14297/jpaap.v6i1.304
- O'Driscoll, D. (2009). A short history of psychodynamic psychotherapy for people with learning disabilities, *Advances in Mental Health and Learning Disabilities*, 3(4), 4 9. https://doi.org/10.1108/17530180200900032
- Obholzer, A. (1986). Institutional dynamics and resistance to change. *Psychoanalytic Psychotherapy*, 2(3), 201-206. https://doi.org/10.1080/02668738600700201
- Paterson, B., McIntosh, I., Wilkinson, D., McComish, S., & Smith, I. (2013). Corrupted cultures in mental health inpatient settings. Is restraint reduction the answer? *Journal of Psychiatric and Mental Health Nursing*, 20(3), 228-235.
 https://doi.org/10.1111/j.1365-2850.2012.01918.x
- Pridding A., Procter N. (2008) A systematic review of personality disorder amongst people with intellectual disability with implications for the mental health nurse practitioner. *Journal of Clinical Nursing*, 17(21,) 2811-2819. https://doi.org/10.1111/j.1365-2702.2007.02269.x
- Purtle, J. (2020). Systematic review of evaluations of trauma-informed organizational interventions that include staff trainings. *Trauma, Violence, & Abuse, 21*(4), 725–740. https://doi.org/10.1177/1524838018791304.
- Rogers, C. R. (1951). *Client-centered therapy: Its current practice, implications, and theory,* with chapters. Houghton Mifflin.
- Rye, E., Anderson, J., & Pickard, M. (2021). Developing trauma-informed care: using psychodynamic concepts to help staff respond to the attachment needs of survivors of trauma. *Advances in Mental Health and Intellectual Disabilities*, 15(5), 201-208. https://doi.org/10.1108/amhid-12-2020-0033

Schuengel, C., de Schipper, J. C., Sterkenburg, P. S., & Kef, S. (2013). Attachment, intellectual disabilities and mental health: Research, assessment and intervention. *Journal of Applied Research in Intellectual Disabilities*, 26(1), 34-46. https://doi.org/10.1111/jar.12010

Shackleton, A. (2016). Have a heart: Helping services to provide emotionally aware support.
In H.K. Fletcher, A. Flood & D.J. Hare (Eds.), *Attachment in intellectual and developmental disability: A Clinician's guide to practice and research* (pp.172-196).
John Wiley & Sons, Ltd. https://doi.org/10.1002/9781118938119

- Sinclair, N. (2018). Transforming care: problems and possible solutions. *Tizard Learning Disability Review*, 23(1), 51-55. https://doi.org/10.1108/TLDR-10-2017-0040
- Skelly, A. (2020). Trauma exposure and the importance of attachment in people with intellectual disabilities. *Bulletin of the Faculty for People with Intellectual Disabilities*, 18(1), 15-19. <u>https://doi.org/10.53841/bpsfpid.2020.18.1.15</u>
- Skelly, A., McGeehan, C., & Usher, R. (2018). An open trial of psychodynamic psychotherapy for people with mild-moderate intellectual disabilities with waiting list and follow up control. *Advances in Mental Health and Intellectual Disabilities*, *12*(5/6), 153-162. https://doi.org/10.1108/AMHID-04-2018-0022

Slakter, E. E. (1987). Countertransference. Jason Aronson.

- Smith, J., Flowers, P. and Larkin, M. (2009). *Interpretative Phenomenological Analysis*. SAGE.
- Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain*, 9(1), 41-42. https://doi.org/10.1177/2049463714541642

Spencer, N., Devereux, E., Wallace, A., Sundrum, R., Shenoy, M., Bacchus, C., & Logan, S. (2005). Disabling conditions and registration for child abuse and neglect: a population-based study. *Pediatrics*, *116*(3), 609-613. https://doi.org/10.1542/peds.2004-1882

- Stickley, T., & Freshwater, D. (2002). The art of loving and the therapeutic relationship. *Nursing Inquiry*, 9(4), 250-256. <u>https://doi.org/10.1046/j.1440-</u> 1800.2002.00155.x
- Storey, J., Collis, M. A., & Clegg, J. (2012). A psychodynamic interpretation of staff accounts of working with people who have learning disabilities and complex needs. *British Journal of Learning Disabilities*, 40(3), 229-235. <u>https://doi.org/10.1111/j.1468-3156.2011.00697.x</u>
- Sweeney, A., Clement, S., Filson, B., & Kennedy, A. (2016). Trauma-informed mental healthcare in the UK: what is it and how can we further its development? *Mental Health Review Journal*, 21(3), 174-192. https://doi.org/10.1108/mhrj-01-2015-0006
- Taylor, J. L. (2019). Delivering the Transforming Care programme: a case of smoke and mirrors?. *BJPsych Bulletin*, 43(5), 201-203. https://doi.org/10.1192/bjb.2019.3
- Truesdale, M., Brown, M., Taggart, L., Bradley, A., Paterson, D., Sirisena, C., & Karatzias,
 T. (2019). Trauma-informed care: A qualitative study exploring the views and
 experiences of professionals in specialist health services for adults with intellectual
 disabilities. *Journal of Applied Research in Intellectual Disabilities*, *32*(6), 14371445. https://doi.org/10.1111/jar.12634
- White, A., Sheehan, R., Ding, J., Roberts, C., Magill, N., Keagan-Bull, R., ... & Strydom, A.
 (2023). Learning from lives and deaths-people with a learning disability and autistic people (LeDeR) report for 2022. Autism and learning disability partnership King's

College London. https://www.kcl.ac.uk/ioppn/ assets/fans-dept/leder-main-reporthyperlinked.pdf

- Wilson, A., Hutchinson, M., & Hurley, J. (2017). Literature review of trauma-informed care:
 Implications for mental health nurses working in acute inpatient settings in
 Australia. *International Journal of Mental Health Nursing*, 26(4), 326-343.
 https://doi.org/10.1111/inm.12344
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15(2), 215-228. <u>https://doi.org/10.1080/08870440008400302</u>.

Appendices

Appendix A: Data extraction form

Study details

Reference (author, year of publication, title of study):

Country:

Design:

Setting/location:

Aims:

Sampling method:

Sample size:

Methods

Demographics (mean age, m/f):

Primary outcome measure(s):

Secondary outcome measure(s):

Analysis:

Intervention

Type:

Duration:

Delivered by:

Comparator(s):

Attrition rate:

Findings

Results:

Adverse events reported:

Appendix B: Example of Thematic Coding: Descriptive Themes

L: denotes Lee and Kiemle (2015)

S: denotes Story and Collins (2012)

HTC: denotes Hudson et al., (2021)

Please note that the descriptive themes are made in the comments, the first comment is related to the first comment icon and so forth. Thematic themes were checked and discussed with my research supervisor Dr Sue Holttum in supervision.

	_	ND Nic Dhonnacha, Katie (k ··· Manipulative, splitting
L: Yeah, cos obviously you might be in for a couple of days and then off for a couple of days, so it's in them couple of days, especially if they know you're off, that you've said one thing, they'll try and manipulate, <u>that's part</u> of the personality disorder.	Ģ	Reply
L: Erm, yeah, it's really <u>structured</u> and the clients know, they know what to expect, they know kind of erm, what we expect from us and what they can expect. We make it very clear about the boundaries that are in place and the structures <mark>that are in place.</mark>	Ģ	ND Nic Dhonnacha, Katie (k ···· Clear boundaries and structures
L: Erm, it can be quite tiring cos obviously, a lot of the behaviours are repeated, over and over, And that's quite frustrating. It can feel quite hard cos you don't seem to move on from things and move forwards.	Ģ	Reply
L: I think it was difficult, more different for me because I was getting the blame from both sides, and I was getting the blame of the staff saying you've not done this, and you've not done that, and getting the blame of the client as well.	Ģ	Nic Dhonnacha, Katie (k ···
L: <u>Well</u> they are, but at other times they can be very supportive of each other. If one of them's having issues about something, they will be very supportive at times, which is nice.	Ģ	No Tiring, frustrating. Not moving forward.
L: Erm, being confident, certainly even when you're not feeling confident, it's coming across as confidentyeah, I think that is really, certainly it feels as if there's a lot of kind of, certainly amongst the clients themselves, with PD, there's a lot more issues, for want of a better term, who's top dog, that kind of pecking order thing.	Q	Reply
L: My immediate thoughts are to make sure that they obviously that I get the, you know, the wounds cleaned up so there is no risk of infection Put the bandages on and all that but I think they are lacking the support emotionally.	Ģ	Criticism from staff and clients.
L: it's like a rollercoaster ride', 'a boiling pot of chaos',	Q ·	ropy
L: Because I always found people I worked with before who had <u>bersonality_disorder</u> as quite narcissistic (Q	ND Nic Dhonnacha, Katie (k ···· Supportive of one another
L: But I suppose that er, it's easier for me to see <u>the women</u> as survivors $()$ erm, in my experience without fail, everyone is, had tragic lives really.	₽	Reply
L: [women] show their feelings more, and tend to carry things home whereas men have their blows and fights even, then it stops.	Ģ	Nic Dhonnacha, Katie (k ··· Importance of portraying confidence
L: They've all got their own special qualities Erm, when you actually see the person, not the personality disorder and not the learning disability. L: After a while you think, well I'd probably be like that if I'd been through what you've been through.	Q	Reply
L: Erm, I suppose a lot of it is, as we should be doing, $ t's$ researching yourself and looking into things and finding things out really, you know, the national guidance an all the rest of it.	\Box	Nic Dhonnacha, Katie (k ··· Social hierarchy 'top dog'.
		Reply

L: If you didn't actually know anything about it and you just met them as a person, they're not always the most likeable people and if you don't know anything about their background.
L: I'm not actually 100%, er, I couldn't tell you <u>what the</u> clinical definition of personality disorder is.
L: It's a person with a personality disorder who <u>has different</u> , different, <u>eger</u> , different [pause] aspects.
L: They can be very kind and caring to each other, which is quite surprising, cause you think ofpeople with personality disorder as not having a lot of empathy for other people.
L: I didn't even realise I was supporting people with personality disorder
L: We didn't spend time with him, we ignored the behaviour, we didn't ignore the behaviour. We tried everything. And then we had this cathartic moment in the MDT [where diagnosis was understood].
L: There is a course, I think we're all crying out to get on it, and stuff, yeah, and it sneeded, it is.
L: I don't know whether my years of working have given me more knowledge and experience than what you could do in a training session.
T: "patients have more <mark>ownership here</mark> , they can negotiate more".
T: " was surprised at the support patients have for each other. was surprised at how well the [TC model] worked"
S: 'We just didn't have a clue'
S: 'It <u>depends</u> who is in power at the moment how we are treated Consultants have complete power. We have nothing'.
S: 'I try not to be pessimistic and look at it positively,'
S: 'I was never angry, I was never, (pause) I was [sic] angry with the situation, but never with the people you're dealing with'.
S: 'So we get the most stressful things that happens to the staff some days is to realise there's only two of us that know what we're doing, and the rest are bank it's heart breaking and that stresses the staff out a lot worse than a fight, and they are not empowered to do anything about it'. (Susie)

ND	Nic Dhonnacha, Katie (k Not likable if you don't take history into account.	•••
Rep	bly	
ND	Nic Dhonnacha, Katie (k Don't know what a PD is.	
Rep	bly	Þ
ND	Nic Dhonnacha, Katie (k Don't know what it is	
Rep	bly	
ND	Nic Dhonnacha, Katie (k PD not having empathy B they can be kind and carin to one another.	
Re	bly	
ND	Nic Dhonnacha, Katie (k Didn't know supporting people with PD.	
Rep	bly	
ND	Nic Dhonnacha, Katie (k Struggle to manage helped with understanding	
Rep	bly	
ND	Nic Dhonnacha, Katie (k Courses/training wanted a needed	 nd

 \square

 \square

 \square

 \Box

 \square

 \square

 \Box

 \square

 \square

 \Box

 \square

 \square

HTC:it's almost like let's move them out because they're suitable, even if they're not quite ready	
HTC:sometimes you do think is that patient really ready [for discharge]	\Box
HTC:sometimes some of the decisions that are potentially being made maybe are not necessarily in the patient's best interest or it's not necessarily what's best for the patient.	\bigtriangledown
HTC:why would you in a sense, usher somebody out of the door that is, still poses a big risk to the public?	\Box
HTC:i <u>t's</u> alright other people saying well we've done everything we can and we've got risk assessmentsyou still feel a lot of the pressure <mark>to protect the public.</mark>	\Box
HTC: In a nutshell, would you want them living next door to you?	\square
HTC:by the time the first e-mail gets from one person to where it's supposed to be at six months have gone <u>by</u>	\Box
HTC: I've been in meetings where three months later I'm sat in the same meeting again and there's ho further progress.	\Box
HTC: But there sn't many places to go Or you have to get a whole new care package.	\square
HTC: There <u>isn't</u> the packages out there to manage people All the people I work with need an independent package. <u>There's</u> not even the physical buildings, let alone the staffing that needs to go with it, and all the policies and procedures that they need to get in place before these people go. Services all over the country are closing beds.	\Box
HTC: <u>So</u> when they're leaving here, they're leaving everything. Security, they're leaving all the people they know	\Box
HTC: You know, some people just don't want to be out of hospital.	\square
HTC: The whole of society has <mark>changed in 10 years</mark> , <u>So</u> the expectations of what you're going to. How they're going to be supported. It's not there anymore.	\Box
HTC: So howwhat are we expecting them to manufacture a society for some people which is not in [pause] keeping with the real world?	\Box
HTC: It's about <mark>using the resources</mark> more that are already out there than probably what we've done in the past.	\square
HTC: recently within the new team we've actually been looking and trying to start new links with police, probation, social care and the secondary care teams.	\Box

P w re	ic Dhonnacha, Katie (k ···· ressure to discharge, thether or not person is eady. 3/02/2024 10:50
Reply	
ND	Nic Dhonnacha, Katie (k ···· Sense that discharge is not in interest of client
Rep	ly D
ND	Nic Dhonnacha, Katie (k ···· Decision to discharge to serve policy and not in best interest of client
Rep	ly 🖻
ND	Nic Dhonnacha, Katie (k Unwise and inappropriate discharge. Potential for harm. Not in interest in public.
Rep	ly D
ND	Nic Dhonnacha, Katie (k ···· Staff feeling responsible and anxious for harm to public.
Rep	ly D
ND	Nic Dhonnacha, Katie (k ···· Unsafe, unwanted.
Rep	ly 👂

Appendix C: Thematic Synthesis: Example of Analytical Themes:

Please note that:

C: denotes Coates and Jones (2019)

H: denotes Huet, (2011).

HTC: denotes Hudson et al., (2021).

S: denotes Storey et al., (2012)

Z: denotes Zarotti et al., (2022).

Controlled and uncontained: 5 contributing studies.

Overseeing forces remote, insensitive or unhelpful.

C: Ridiculous... I had a client he came into the office and tried to get a knife... Police came and wouldn't take him... I had to stay in this house alone for another two hours, with someone who just tried to get a knife to stab me.

C: [police involvement] can be disproportionate and even inconsistent... examples where you don't get the desired response ... and then there are others who get picked up quite easily... I don't think it's always consistent unfortunately.

C: They [police] kind of laughed he victim away (reporting a crime).

H: [Senior professionals] are 'quite a long way from the clients and can't really see what is really happening'.

HTC:[of Transforming Care pressures] ...why would you in a sense, usher somebody out of the door that is, still poses a big risk to the public?

HTC: I feel like [Transforming Care] police the CPA process.

S: 'It is the main reason for the problems on here is the mix They don't consider who they already have got in. ... no control ... how can I describe it? They can bring in anyone they want and they do.

S: '[staff] don't really want formal support, they don't like it, they're suspicious ... 'Why have you come to see me?' 'There's nothing wrong with me.

S: 'It depends who is in power at the moment how we are treated ... Consultants have complete power. We have nothing'.

S: We might pretend we have (power and control) but we have nothing.

S: 'So we get the most stressful things that happens to the staff some days is to realise there's only two of us that know what we're doing, and the rest are bank ... it's heart breaking ...

and that stresses the staff out a lot worse than ... a fight, ... and they are not empowered to do anything about it'.

Z: We don't have a psychologist in our team at the moment. (...) Our psychologist would mainly be doing things like autism assessments. (...) I can't remember him doing any PD work.

Z: We've gone through lengthy periods without having psychiatry.

Z: It's around that recruiting and training the right people. People don't stay with a single provider for long. (...) They will go where they can get an extra four quid an hour. And I think, as a result services are leery of investing in their staff team.

Appendix D: Detailed Quality Review:

CASP Checklist:

Study Reference: Taylor, Jon, and Sarah Trout. "Lessons from the front line: working with offenders with learning disability and personality disorder in a high secure therapeutic community." *Mental Health Review Journal* 18.1 (2013): 44-52.

1. Was there a clear statement of the aims of the research? No

The aims are referred to in the abstract and to an extent in the title of the paper, however, the aims are not clearly stated in the body of the paper. The abstract states the following:

'The aim of this paper is to provide an overview of the experiences of nursing staff providing a residential treatment programme for high-risk offenders with an intellectual disability and personality disorder'. The paper does not go on to speak in great depth to the nurses' experience, in fact, the majority of the words are describing what a therapeutic community is, and also speaks in some depth to the findings of a different paper. Perhaps the paper was trying to do too much, cover too much ground, which is why it is difficult to discern what the aims are. The goals are blurry, not clearly stated, nor are they achieved.

2. Is a qualitative methodology appropriate? Yes

If the aims are to be taken at face value, qualitative methodology is appropriate meet their aims. They state that their aims are to provide an overview of the experiences of the nursing team, therefore a thematic analysis of a focus group on this topic has face validity. They do not provide a rationale for why they chose thematic analysis, or why the data analysis was in a group setting. One would wonder why IPA wasn't considered seeing as it is a homogenous participant pool for which the experience is emphasised as the focus. It may be related to worries about bias, but there is no reference to this in the text. There is no reference whatsoever to the reason for choosing thematic analysis and why it was their analysis of choice.

- 3. <u>Was the research design appropriate to address the aims of the research? Yes</u> *The design is appropriate to meet their aims. It is a strength that the EssenCES outcome measure was used in addition to the thematic analysis as it opens up rich opportunities for analysis and comparison. The strength of EssenCES measure is that they can compare the present data to norms nationally and internationally. The paper fell short of the potential that this design offered them in terms of the scope of comparison it offered them.*
- 4. Was the recruitment strategy appropriate to the aims of the research? **Can't tell** No reference is made to how staff were recruited to the study, who was invited, who accepted, if there was an incentive for participating or pressure to seeing as the writer was a senior clinician in the setting. It is expressed that participants for the focus group 'volunteered', which suggests neither incentive nor pressure. It would have been helpful to hear more of the considerations they gave this process. They did note that because of the voluntary nature of participation that the participants who were involved may be offering a biased view of the therapeutic community.

5. Was the data collected in a way that addressed the research issue? Yes

Data collection appears to be appropriate considering the expressed aims. They set it up in such a way that they would have several avenues of data, such as collecting EssenCES measures at several time points to observe changes over time and focus groups over two sessions to get a deeper understanding of the experience of the participants. It seems a sensible way to approach data collection. They also allude to some preparative consultation in relation to developing the interview schedule 'Feedback received during training of ward staff was used to design a semi-structured interview format in order to shape the discussions'. This is interesting as it seems as though they put a lot of thought into the focus groups and getting the most out of the schedule, but then didn't go on to actually say what came of this in the write up. I wonder what was going on there?

Has the relationship between researcher and participants been adequately considered?
 <u>No</u>

There is no reference to this in the text whatsoever. It might be that they gave this a lot of thought but that they didn't write about it, considering how much omission there appears to be in the text. The research is in a niche setting and the researchers come from this niche setting, whereby one may make speculate if this is influenced by a) the researchers' passion for the field and b) their desire to share the results in a positive light. It's impossible to say, because it isn't reported, which is a shame.

7. Have ethical issues been taken into consideration? No

No references to this whatsoever. They made very odd decisions in the paper regarding how many words they dedicated to describing what a therapeutic community is, detailed descriptions and some data from another paper, and then little to nothing on reporting the results of their own research and their process regarding ethics and rigour. The result is a confused and confusing body of text, which leaves one with the impression that something is being obfuscated or avoided, maybe consciously, maybe unconsciously, particularly in relation to the result of the focus groups and thematic analysis. There are some ethical issues presented by their write up, whereby minimal actual data regarding the thematic analysis is presented to the reader. This means that the reader cannot actually understand what was said, how it was interpreted, and whether the analysis reliable or valid. The greatest victim in this is the participants who gave their time to attend the focus groups, only to have their contributions largely erased and neglected in the write up. It may be that they included so little of the participants' data because it could undermine the nurses, who were very easily identifiable, or that it undermined the therapeutic community maybe? It's difficult or impossible maybe to gauge where the issues lie, in the process, in the write up, or in both.

8. Was the data analysis sufficiently rigorous? Can't tell

Some references were made to measures taken to ensure quality and rigour in the qualitative analysis. They refer to consultation prior to data collection in the thematic analysis to guide the construction of interview schedule. They seemed to have designed this thoughtfully in order to gather the data they wanted, which is 'to learn about the experiences of the staff'. They describe recording being taken, and being coded by one of the researchers, which were then audited to ensure inter-rater reliability and ensure the credibility and validity of the themes. Because so little of the actual data they gathered is presented, the reader cannot make one's own mind up about the content of the thematic analysis, let alone the validity of the writers analysis or interpretations. This coupled with no references whatsoever to reflections on sources of bias, and measures taken to address this in the analysis leaves one with less confidence in the rigour of their analysis.

9. Is there a clear statement of findings? No

This appears to be the defining failing of the paper. The qualitative papers are presented just in terms of the titles of the themes and subthemes. These titles do not appear to be in vivo quotes, which is a shame, as it would have offered a lot more context. Because the vague and broad titles have in most cases no direct source data to elucidate and clarify them, one cannot actually understand what they mean, what they signify. I have to wonder what was going on here... Did they want to protect the quotes of the participants because they could be identified easily? They didn't speak to this at all, but it may have been at play. Were they uncomfortable with some of the findings? Did they think that the reader could glean more from the titles because they themselves were so clear in what they meant?

10. <u>How valuable is the research? Not very valuable.</u>

Because of the novelty of the field and setting the authors spent a huge amount of time outlining context and far less describing their findings, which greatly undermines the value of it. The paper is not easily replicable because of issues in reporting. The sense of the nurses' ideas and experiences is difficult and nearly impossible to access, which is at direct odds with their expressed aims.

It may offer some value in terms of process, despite falling down on content. It appears as though their aims as expressed in the paper weren't telling the whole story, because what they said they wanted and what they produced are at odds with one another. Despite being a deeply flawed piece of research, it still has value because of the empirical context around it, in which there is so little data. Its contribution is small, but it has a contribution none the less.

Appendix E: Interview Schedule

- 1. Can you tell me a little about your day-to-day work? What sort of things would you be doing in a typical day?
- 2. What are some of the highs and lows of your day-to-day work things that leave you feeling good and not so good?
- 3. What are some of the things in your day-to-day working context that you find helpful for your work, and less helpful?
- 4. What sort of training or guidance, if any (apart from the training that is the focus here) have you found helpful if any?
- 5. When did you attend the training? How did you come to attend it? (e.g. choice, told to attend) Firstly want to get some facts and then I'll get to talk more.
- 6. What stands out in your memory as something that has stayed with you from what you learned?
 - a. How did you feel during this learning? Prompt what it is that seems so valuable or why.
- 7. Can you tell me about what it was like learning about some of the topics spoken about (such as trauma, attachment, splitting, unconscious communication and the "middle ground")?
- 8. What thoughts, if any, have you had about these concepts since learning about them? Especially in relation to your day-to-day work?
- 9. Have you noticed any differences at all in how you respond to clients since learning about these concepts?
 - a) Prompt: What about when they become angry or distressed?
- 10. What in your experience helps/hinders you in your work with service users who are expressing anger or distress?
- 11. Have you noticed any differences at all in how you work together as a team since learning about these concepts?
- 12. Is there anything else you can think of that we haven't covered, that you feel is important to tell me regarding your experience of the training, or whether it met your expectations or anything else about it?

Prompts: That's interesting, can you tell me more about that?



CONSENT FORM

Title of Project:	Exploring the Experiences of Psychodynamic Training on
	Healthcare Workers who work with Intellectual Disability and
	Personality Disorder.

Name of Researcher: Katie Nic Dhonnacha

Contact details:

Address:	Salomons Institute for Applied Psychology Canterbury Christ Church University Lucy Fildes Building 1 Meadow Road Tunbridge Wells TN1 2YG
Tel:	01227 927113
Email:	kn165@canterbury.ac.uk

Please initial box

- 1. I confirm that I have read and understand the participant information for the above project and have had the opportunity to ask questions.
- 2. (If applicable) I confirm that I agree to any audio and/or visual recordings.
- 3. I understand that any personal information that I provide to the researchers will be kept strictly confidential and in line with the University <u>Research Privacy Notice</u>
- 4. I understand that my participation is voluntary and that I am free to withdraw my participation at any time, without giving a reason.
- 5. I agree to take part in the above project.

Name of Participant:	Date:	Signature:

Name of person taking consent (if different from researcher)	Date:	Signature:
Researcher:	Date:	Signature:

Appendix D: Information Sheet

Information about the research

Study Title

Exploring the Experiences of Psychodynamic Training on Healthcare Workers who work with Intellectual Disability and Personality Disorder.

My name is Katie Nic Dhonnacha and I am a trainee clinical psychologist at Salomons Institute for Applied Psychology. As part of my doctoral research, I am exploring the experiences of people who work with people with an intellectual disability and a personality disorder, and their experience of training teaching trauma-informed approaches to care. This piece of research is supervised by Dr Sue Holttum, senior lecturer at Salomons Institute and Emma Rye, consultant clinical psychologist with Kent and Medway NHS Trust.

I would like to invite you to take part in this research. Before you decide whether or not you would like to participate, it's important to understand why the research is being done and what it would mean for you.

A note on language.

The term Personality Disorder is controversial and can be particularly contentious when used in the context of people with intellectual disability. As it is readily understood as a clinical term across different professions in mental health caring roles, the researchers have decided to use it in this study.

What is the purpose of the research?

The purpose of the research is to explore your experiences of the training, in order to better understand what it was like for you, and if it influenced your thinking or practice following the training.

Why have I been invited?

You have been invited to take part in the study because we are interested in your perspective as a health care assistant who works closely with people with an intellectual disability and personality disorder, and have completed the training titled 'A Trauma-informed Approach to Caring for People with a Personality Disorder and an Intellectual Disability'.

Do I have to take part?

Participating in the research is entirely your choice. If you decide to participate, I will ask you to sign a consent sheet. If you change your mind, you are welcome to withdraw prior to or during the interview without penalty or explanation. Following this, you have 14 days to withdraw consent.

What would taking part involve?

Participating would involve an interview with me via Zoom, or your preferred video communication platform. The interview is semi-structured, meaning it follows a loose plan of questions. The interview would be between 60 - 90 minutes with comfort breaks inbuilt if desired. The interviews will be recorded using an audio recording device. The purpose of the recordings is so that I can fully and faithfully capture all the information you provide, which is essential for the later analysis of this information.

Expenses and Payments

You will be compensated $\pounds 10$ for your participation in the study in the form of a voucher. This is funded by Canterbury Christchurch University.

What will I be asked to speak about?

In the interview you will be invited to answer questions based on your personal experience of the trauma-informed training, and how it may relate to your work. You are welcome to refuse to answer questions if you are not comfortable with them. You can also stop the interview or take a break at any time without penalty or explanation.

What are the possible risks or disadvantages of taking part?

The subject matter may elicit feelings of distress or discomfort for you, for example if a question touches on a topic that is of personal sensitivity to you at the time of interview. You are welcome to refuse to answer questions that you are not comfortable with, and to stop the interview without penalty or explanation.

What are the possible benefits or advantages of taking part?

You may get a sense of wellbeing from contributing to an under-researched body of knowledge. Although this may not benefit you directly, we hope that it would contribute to an evidence base which may be of benefit to others in future.

Will my information be kept confidential?

Yes. All of your information will be handled confidentially in line with ethical and legal best practice.

The information you provide in the interview will be audio recorded and then transcribed in a way that is anonymised and coded to protect your information. The recordings and transcriptions will only be accessed by me and two research supervisors. Once the transcription has been completed and checked for accuracy, the recordings will be deleted.

Paper information will be stored in a locked cupboard, or if stored electronically will be password protected.

The data collected will be used only for the research. The anonymised transcripts will be stored for ten years in accordance with guidelines from the Medical Research Council, after which it will be destroyed. You have the right to check your data and correct any errors.

There are rare instances in which your information would be shared with others; for example, if you were to disclose something that indicated risk of harm to you or others. If this arises, the researcher will inform you and discuss it with their supervisor. If the risk is considered to be serious, your line manager would be informed. The appropriate authorities may also be

informed if it is deemed necessary, such as the police. In these cases, data that had been collected would not be included in the research.

What will happen if I don't want to carry on with the study?

If you wish to withdraw from the study for any reason, you can do so without penalty, or having to provide a reason. If you withdraw during the interview, I will ask you if you are happy for me to use the data you provided prior to withdrawal. If you are not happy with this, then your data will be destroyed, and I will not collect any further information from you. Following the interview, you can inform me within 14 days if you would like to withdraw from the study and the data you have provided will be deleted. Following 14 days, it will not be possible to withdraw. Please consider this carefully prior to participation.

What if something goes wrong?

If you have concerns about any aspect of the study, I'll do my best to address them with you.

If the concern is about your wellbeing, information regarding some of the supports that are available to you will be provided.

If your concerns regard the research or your treatment during the study, I will do my best to address these with you, however, if you remain unsatisfied, you can complain formally using the NHS complaints procedure. You may also contact Dr. Fergal Jones, Research Director at Salomons Centre for Applied Psychology (email <u>fergal.jones@canterbury.ac.uk</u>).

What will happen to the results of the study?

The results of the study will be reported in a doctoral thesis and may be published in a psychological academic journal. You will not be identified in this journal, however, it may contain anonymised direct quotations from you.

If you wish to, you will be contacted with a debrief and explanation of the findings. If you do not wish to be contacted with the results, you will not receive further correspondence.

Who has authorised the research?

The study has been reviewed by the Health Research Organisation and Salomons Centre of Applied Psychology ethics board.

Who is funding the research?

The research is funded by Canterbury Christchurch University.

What if I have further questions?

If you have any further questions, feel free to contact via email on $\underline{\text{kn165}}$ <u>acanterbury.ac.uk</u>. If you would prefer to be contacted by phone, email your contact details to the email address provided and I will contact you accordingly.

Appendix G: Reflexive Diary

Entry 1:

My original research proposal has been criticised for appearing too like a service evaluation, which is worrying. A revised version has now been submitted and I'm hopeful that it will be more acceptable. I am minded of how important it is to sway prospective participants away from this understanding and accordingly have revised my interview schedule.

Entry 2:

I've been thinking about research questions this morning and it feels like the changes required treading quite a tricky balance in terms of the introduction of specific dynamic concepts without sounding as though I'm testing their knowledge. I feel as though I'm going to have to emphasise in the 'blurb' that this isn't the case. I removed the repetition of 'the training' from the questions in order to probe around their experience of the knowledge more generally, hopefully this helps in moving it away from service evaluation territory. I am particularly aware of not wanting to position myself as an intimidating academic as this might hinder our conversation.

Entry 3:

Consultation has been so interesting. Fascinating to hear about the work lives and passion within the workforce. It's rewarding to utilise their feedback in the design. They have suggested that this population may be cagey and reticent to share their thoughts because the work can be so distressing and that they may be quite sensitive to feeling judged or misunderstood. Several people recommended that I share my own history in this field, which I felt an initial reticence to. I had to grapple with the tension between my impulse and integrating feedback so as to honour the participation.

136

Entry 4:

My first interview, it felt so good to get up and running in data collection. I'm struck for my love the area and managing my impulse to tell people I'm in their corner. I remember felt frustration with the participant that she wasn't going deeper. Mirroring with her and her client, self-focused. I listened back and found that she had been open and generous and that my frustration didn't seem to manifest, which was a relief.

Entry 5:

I find myself struck by how much the training is standing out in the memory of participants. Entry 6:

Recruitment and the training has been affected by Covid. Things are so hard for everyone. I'm so grateful for very helpful and kind supervisors. They've been decent. I'm moved that people are volunteering for my study

Entry 7:

My second participant was charming but gave less of himself. Gave a polished interview. Interested in managing my impression of him. He was very passionate and caring, it made me feel hopeful. We both seemed to be trying very hard to exude "I'm not a threat".

Entry 8:

A very moving interview with a PBS practitioner. Not realising her expertise and she seemed on a mission to improve the world for People with ID. Evangelical about the importance of her learning. Her experiences of frustration were familiar to me from my own experiences. I had to hold in mind not to over identify with her. I had to remind myself not to get things muddled in where do I begin and you end. NB: Keep this in mind at point of analysis. Entry 9:

I felt kind of intimidated and out of my depth talking to this man. He had been in the field for nearly as long as I've been alive. He was cut off, pragmatic, but direct. He gave very

137

informed answers to my questions and seemed very motivated for things to improve, but almost nothing of himself or his experience. It didn't feel hostile or deliberately withholding, but it made me think of ways he may have had to shut himself down to survive in the job. Entry 10:

An odd conversation with a man who has been a support worker in this field for over a decade. Affable and warm, I noticed the more distressing the content is, the more sterile and bland the jargon is. Sometimes is so sanitised and had a mild anaesthetic effect. He didn't take home some of the essential messages. I got the sense that he was in 'pretend mode' in mentalising terms.

Entry 11:

A woman who came across as a bit flat in her facial expression and tone of voice, spoke so genuinely and warmly for her clients. Was direct about how much she missed a client she'd supported for many years who had been stepped down, which left me feeling quite emotional. Her manner could be so robotic, it was odd, like she'd shut down an essential part of herself. Entry 12:

I have returned from maternity leave and have had a great deal of trouble recruiting. It has been feeling a bit hopeless. My final two participants went cold on the line, which was so upsetting as it meant I will likely miss the submission deadline. It's a hard line to tread and you don't want people to get wind of your desperation.

Entry 13:

Penultimate client, it was an interesting, but odd and sometimes jarring conversation. She didn't seem to connect with the material at all. Her use of transactional language made me feel quite uncomfortable. I found myself perturbed by some of her feedback. I also found myself wondering why she volunteered, what motivated her to.

138

Entry 14:

My final participant, I feel immense relief, it feels like my life is back under my control now because I can finally produce a Part B. The interview itself was so fascinating, the vivid imagery of this woman's spoken word was a joy to witness. I found myself very much admiring her but also wondering how long she would last in the field, as it sounded like it was too much for her to bear at times.

Entry 15:

The process of data analysis has been quite inspiring. I feel so grateful that so enjoy this subject matter, it's endlessly fascinating to me, which has helped me soldier on.

Appendix H: Example Transcript

Raw data	Descriptive notes	
	Linguistic observations	
	Conceptual observations	
A: Ok., so, to start us off, can you tell me a little		
bit about your day-to-day work?		
B: Er, yeah, well I'm a positive support	Hesitant. Error in title. Unsure of role? Or	
behaviour person so I work on the PBS team of	validity of role?	
[PLACE]		
A: Mmhmm		
B: Care, erm, and basically we look afterthe,	Hesitant, unsure language.	
the two clients I look after are autism. Er, one's	Autism as the person. Differentiation between post-traumatic stress and PD.	 Nic Dhonnacha, Katie (k. Client Group complex
got post-traumatic stress, erm, and the other		
one who's got a personality disorder		
A: Mmm		
B: So, they live in like their own houses and we	Repetition of 'support'.	
go in and we support them with, erm, 24we,	The role is to care for and support. Involved and	
we do 24 hour care so and we do support 'em	intimate, 24 <u>hour</u> .	 Nic Dhonnacha, Katie (k. Involved and intimate role
sort of with day to day		
A: Mmm		
B: things, erm, <u>and.</u> erm, we also do sleep-ins		
and night wakes		
A: Ok. And <u>so</u> what sort of things would you be		
doing kind of in a typical day in your role?		
B: Haha @ er, it depend which client I'm		
working with @ coz they're very, very two that,	Unsure, stumbling linguistically.	
er, they're very two that are completely		 Nic Dhonnacha, Katie (k Complex role, dynamic
different	Caring for two people who are very different.	
A: Mmm		
B: Shall we say?		
A: Yeah		
B: Erm, one is, lacks mo-, motivations	Unsure, lacking in confidence expressing herself.	 Nic Dhonnacha, Katie (k MH Jargon
A: Mmmhmm	Using clinical descriptors to describe person.	

P. You have to the and get has motivated arm	Involved role. Solf Herm	
B: You have to try and get her motivated, erm,	Involved role. Self-Harm. - This is-presented as-self-harm less complex,	Nic Dhonnacha, Katie (k.nic-dhonnacha165 Complex client group
she can self-harm where the other guy he's	commonplace?	
more, he's more complex. He's, he's got the	Motivation a good thing.	 Nic Dhonnacha, Katie (k.nic-dhonnacha165 Complex client group
motivation so he'll do stuff like he'll say if he	Difference noted in the 'doing' and in the	
wants to go out for a walk, erm, or if he wants	'getting to the point of doing' of the role.	
to go to the shops we take, take him out in our,		
erm, staff cars like up to [PLACE] or [PLACE] or		
and stuff. Ok, it's been a bit diff-, different	Lockdown affected the role.	
because of <u>lockdown</u>		
A: Mmm		Nie Dhenneche, Katie (Ir nie dhenneche 165
B: but he's more, he's more complex. You have	Repetition of complex. One has to be alert on	Nic Dhonnacha, Katie (k.nic-dhonnacha165 Complex and dynamic role
to be on the pall with him more than what you	the job.	
do the other lady we support because he has,		
erm, disassociated episodes	Clinical descriptors, obfuscating-accessing	Nic Dhonnacha, Katie (k.nic-dhonnacha165 MH Jargon
A: Ok	clearer access of him or her experience of him?	
B: So, he's a lot more, he's a lot more		
complexed	Linguistic fumble of bland clinical term	
A: Mmm		
B: with, with the support because he can be ok	Unexpected changes.	Nic Dhonnacha, Katie (k.nic-dhonnacha165
and talking to you one minute and the next all		- Unstable and changeable work environment
of a sudden he'll go into a disassociated episode	Sterile language, difficult to understand.	- Nic Dhonnacha, Katie (k.nic-dhonnacha165
A: Ok		MH Jargon
B: Erm, whereas she will, with her she, she'd do		
stuff but she, she wants, she needs a lot of		Nic Dhonnacha, Katie (k.nic-dhonnacha165 Effort in the role
prompting to do things	Clinical language.	
		Nic Dhonnacha, Katie (k.nic-dhonnacha165
B: Erm, sometimes you just get a no. you'll say	Rejection of suggestions. Powerful.	Tricky relationship. Rejecting. Uncooperative
to her oh well how about we do <u>this</u> and <mark>it'll be</mark>		
no and that's it		
A: Mmm		
B: @		Nic Dhonnacha, Katie (k.nic-dhonnacha165
A: Yeah		- Helplessness? Impotence?
B: That's, that's, that's it, that's the answer	Finality of the no.	Nic Dhonnacha, Katie (k.nic-dhonnacha165
A: Hmmm		Inflexible clients
		I

Appendix I: Ethical Approval



Salomons Institute for Applied Psychology

Katie Nic Dhonnacha Trainee Clinical Psychologist Canterbury Christ Church University

04 March 2021 Direct line 01227 927094 E-mail Margie.Callanan@canterbury,ac.uk Our Ref V:\075\Ethics\2019-20

Dear Katie,

Outcome: Full Approval

Exploring the Experiences of Psychodynamic Training on Healthcare Workers who work with Intellectual Disability and Personality Disorder.

Thank you for addressing the points raised by the Ethics Panel so thoroughly, we are pleased to offer you approval for your proposed study.

We look forward to receiving a short report on progress and outcome on completion of the research, in order to complete our file. The report should be the same one that is provided to your participants. Please note that any changes of substance to the research will need to be notified to us so that we can ensure continued appropriate ethical process.

We wish you well with your study and hope that you enjoy carrying it out.

Yours sincerely,

Margo Callanan

Professor Margie Callanan Chair of the Salomons Ethics Panel

Cc Dr Sue Holttum

School of Psychology and Life Sciences Faculty of Science, Engineering and Social Sciences

Canterbury Christ Church University 1 Meadow Road Tunbridge Wells Kent TN1 2YG (UK) Tel +44 (0)1227 927166 www.canterbury.ac.uk

Professor Rama Thirunamachandran, Vice-Chancellor and Principal

Registered Company No: 4793659 A Company limited by guarantee Registered Charity No: 1098136