“What has happened to you?”: Re-humanising Services for People with Learning Disabilities

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Lay Summary

Asking "What has happened to you?": Changing the way Services Support People with Learning Disabilities

Background

There are people within our communities who find it harder to learn, understand, and/or communicate, which can make everyday activities more difficult and may mean that they require support. These individuals are often diagnosed with and labelled as having a 'learning disability'. A 'learning disability' is a term that was created by professionals to describe individuals for the purposes of budgeting, planning services, and doing research. However, people who are given this label are, and should be described as, many other things including friends, relatives, partners, parents, and community members. People are usually born with differences in their thinking abilities and get a diagnosis of a 'learning disability' when seeking support for difficulties through health and social care services.

Due to these differences and difficulties, individuals face stigma, discrimination, inequalities, and abuse at high rates throughout their lives, significantly more than other people in society. This may be due to negative attitudes towards people with disabilities in society and ways that individuals diagnosed with learning disabilities were treated by services in the past. People were commonly segregated in institutions away from their families with little to no choice over their own lives. There have been some changes since then, with a shift in services towards 'supported with' rather than 'cared for', but many issues of mistreatment persist. Also, individuals who are described as having learning disabilities are still more likely to be diagnosed with severe and long-lasting mental health conditions and have considerable unmet needs.

Unmet needs and distress can be caused by a lack of power and abuses of power in people's lives. People with learning disabilities often have very little influence over their everyday life and what happens to them. This lack of power can also happen to people when they seek support from health and social care services. Professionals who work in services are powerful and make decisions for people, hopefully in their best interests but this is not always the case. So, some professionals have highlighted that it is important to think about power imbalances and the impact on people's lives.

Paper 1: The Power Threat Meaning Framework and People with Learning Disabilities: Psychological Professionals' Perspectives

The first paper in this piece of work was a research study that explored a new framework called the 'power threat meaning framework'. This framework was developed by psychologists and adults with lived experience of mental health difficulties. It says that we should consider what has happened to us, rather than thinking there is something wrong with us if we experience difficulties with our mental health. This is based on lots of research that suggests mental health difficulties are linked to difficult things that have happened in people's lives (sometimes called 'trauma' or 'adversity'). The power threat meaning framework focuses on negative experiences of power, how these can feel very threatening, the meaning we make of the experiences, and how that may explain the ways we respond. However, there hasn't been any research to look at how the framework might apply to the lives of, and be used to support, people with learning disabilities.

To explore this for the first time, I separately interviewed eight professionals who use the power threat meaning framework in their work in learning disability services, to ask them about their experiences. The professionals were all from a psychology background. I then gathered all their answers and thought about what they might mean, focusing on the things they agreed on. This is a type of data analysis called reflexive thematic analysis, which thinks about words and descriptions of things rather than numbers. This is called 'qualitative research'. There were four main themes that I created from the interviews. These suggested:

1. Professionals thought the power threat meaning framework was relevant to the lives of people with learning disabilities and their work in learning disability services

2. They had mainly used the framework in their work with people's carers and other professionals involved in their care to think about power imbalances, what had happened or was happening to a person, and to try and increase compassion for people
3. Some professionals had thought about using it more widely in their services to help the whole service to think about trauma and difficult experiences that both staff and people with learning disabilities may have experienced
4. But they had experienced challenges using the framework within services as it differs to medical and psychiatric views, which are popular in lots of services

The findings of the study suggest that the power threat meaning framework could help professionals and carers to think about and support individuals in a more empathetic and empowering way. However, the study did not find out what people with learning disabilities think about the framework. It is important that more research is done to find out what different people think, and to measure if using the framework leads to better outcomes for people.

Paper 2: What is Known About Using Trauma-informed Care Within Services for People with Learning or Developmental Disabilities?

The second paper reviewed other research and papers that have been published on 'trauma-informed care' used within organisations for people with learning disabilities or 'developmental disabilities', such as autism. Trauma-informed care is another framework that says it is important to think about what has happened to people, because research shows that lots of people have experienced 'trauma', such as abuse in childhood. Services that use trauma-informed care try to help all people, both people who use services and people who work in services, to feel safe and empowered by being trustworthy, giving choices and collaborating. As research shows that people with learning or developmental disabilities experience more trauma than other people, it would make sense that trauma-informed care should be used in services that support these individuals.

However, there has not been much research about trauma-informed care in this area, so to gather and explore the existing literature a 'scoping review' was completed. This involved searching three databases and screening 69 papers, of which 23 were about trauma-informed care being used in different services that support people with learning or developmental disabilities. I gathered details from each paper, looked at the findings and collected the key information. The findings showed that:

- There are opportunities for using trauma-informed care within these services
- Some specific services are using parts of trauma-informed care for people with various types of learning or developmental disabilities, like autism
- Trauma-informed care should be used across the whole organisation as part of the culture, including for employees
- There are challenges and barriers to using trauma-informed care in these services. For example, staff need knowledge and training, which has led to new research developing trauma-informed care training programmes

However, we need more research to explore if and how using trauma-informed care leads to better outcomes for people with learning or developmental disabilities.

Conclusions

There is overlap between the power threat meaning framework and trauma-informed care; they both focus on thinking about what has happened to people, rather than what is wrong with them. Both approaches could help to transform services for people with learning disabilities into more empowering, equitable, and compassionate systems to provide better support for people. The findings of both pieces of work will be shared to hopefully provide recommendations for future research, and ideas for services and policies for people with learning or developmental disabilities.

Paper 1: The Power Threat Meaning Framework and People with Learning Disabilities:

Psychological Professionals' Perspectives

Abstract

People with learning disabilities are disproportionately disempowered and often experience numerous psychosocial adversities and consequent psychological distress. The power threat meaning framework (PTMF) was designed to centre disempowerment in the conceptualisation of psychological distress and is gaining momentum within the field of mental health. The PTMF is progressively being applied and researched in various contexts, though has not yet been empirically investigated in relation to people with learning disabilities. This research aimed to explore professionals' experiences of drawing on the PTMF in learning disability contexts to provide novel insight into the applicability of the framework, including the opportunities and challenges in this setting. Semi-structured interviews with psychological professionals (*N* = 8) who work with adults with learning disabilities and draw on the PTMF in their work were analysed using reflexive thematic analysis. Four themes were interpreted: (1) "Raising the flag" for PTMF and People with Learning Disabilities, (2) Enhancing by Asking, "What's happened to this person?", (3) PTMF as a "System-wide Approach", and (4) "There's still a way to go" for PTMF in Learning Disability Contexts (and beyond). Findings indicated that professionals perceived the PTMF as conceptually applicable and particularly relevant to the lives of people with learning disabilities and thus are beginning to draw on the framework systemically to enhance thinking around individuals by asking, 'How is power operating in this person's life?'. Opportunities were identified for the PTMF to be adopted as a trauma-informed whole systems approach, though not without navigating challenges within current contexts. Yet, professionals perceived the PTMF as a timely antidote in an ongoing pursuit for the empowerment of people with learning disabilities by the support services they often rely on. Implications for clinical practice and future research are discussed.

Key words: people with learning disabilities, power threat meaning framework, reflexive thematic analysis, psychological distress, psychological professionals

Introduction

People who self-define, or are described, as having a learning disability too often experience oppressive and disadvantaged circumstances throughout their lives. This disempowered position is well documented: longstanding and multifaceted discrimination has produced such circumstances where people diagnosed with a learning disability are more likely to be deprived (Tyrer et al., 2022), to not be in employment (Giri et al., 2022) or intimate relationships (Black & Kammes, 2019), and to experience health inequalities (Nocon et al., 2008), and lifelong victimisation and abuse (Fisher et al., 2016; McDonnell et al., 2019). Even seemingly ordinary experiences are not a given for this population, often having to live in places they did not choose with people they do not know (D. S. McNally, 2008), and be supported by changeable paid carers who are not family or friends (Pockney, 2006). Moreover, due to increasing austerity disability services are vastly underfunded, leaving people with inadequate support to meet their needs and their chances of leading an ordinary life remaining out of reach (Malli et al., 2018). Arguably, this disempowerment is mainly due to living in an ableist society where intellect is desired and differences are discriminated (Bogart & Dunn, 2019; Hall, 2010). Though given inclusive and empowering circumstances the possibilities for people with learning disabilities are plentiful (Salman, 2020), proving that *"no one is fully trapped in a uniform disadvantaged position"* (Link & Phelan, 2001, p. 380).

The power in the use of terminology to describe people as having a learning disability warrants thoughtfulness first and foremost. Throughout this paper the terminology 'learning disabilities' is used to reflect the most widely used term in the UK (Gates & Mafuba, 2016), despite increasing use of 'intellectual disabilities' within medical and academic discourses. Notably, individuals themselves can experience discomfort around such diagnostic terminology and tend to create personal definitions (Kenyon et al., 2014; Monteleone & Forrester-Jones, 2017). The diagnosis of a learning disability refers to a diagnostic criterion encompassing both a significant impairment in intellectual functioning and marked challenges in adaptive functioning, both originating in childhood (American Psychiatric Association, 2013). Though, this group of people are exceptionally heterogeneous and arguably only share this diagnostic criteria (Burack et al., 2021). However, health and social care services often require a formal diagnosis as proof of eligibility for support (Whitaker, 2004). Thus as a label, ‘learning disability’ can positively benefit people by providing access to services, but importantly it can equally act to exclude, stigmatise, and disempower (Cluley et al., 2022; G. M. Thomas, 2021). Therefore, it is necessary to reflect on such terms, as their use powerfully affects the lives of people with learning disabilities (Cluley, 2018), including their identity formation (Gillman et al., 2000). As posited by Wendell (1996, p.32), *“how a society defines disability and whom it recognises as disabled are of enormous psychological, social, economic and political importance, both to people who identify themselves as disabled and to those who do not but are nevertheless given the label”*.

Given the psychosocial adversities in their lives, it is unsurprising that people with learning disabilities are more likely to be diagnosed with mental health problems compared to other people (Daveney et al., 2019; Hughes et al., 2019) and commonly access mental health services for support (Smiley, 2005; Whittle et al., 2018). This is not to undermine the resilience of people with learning disabilities, but highlights that experiencing increased adversities means resilience may be challenged more than other people (Emerson, 2013; Wigham & Emerson, 2015). Indeed, studies examining the prevalence of mental health conditions have revealed between 30-50% of adults with learning disabilities have a psychiatric diagnosis (Bowring et al., 2019; Hughes-McCormack et al., 2017; Mazza et al., 2020) and are up to 10.8 times more likely to have a ‘severe mental illness’ compared to the general population in the UK (Perera et al., 2020). Of note, prevalence rates vary widely likely due to inconsistencies in definitions and whether studies include ‘challenging behaviour’ as a mental health problem (Smiley, 2005), as well as under-recognition and diagnostic overshadowing (Mason & Scior, 2004). The term ‘psychological distress’ was chosen for this paper to encompass emotional and behavioural manifestations of distress to acknowledge their overlap (Dagnan, 2008). Thus, a recent UK cohort study drawn from primary care data of 33,016 individuals revealed that 70% of adults with a learning disability have been recorded to experience psychological distress, that is either an identified ‘mental illness’ (34%) or ‘challenging behaviour’ (36%) (Sheehan et al., 2015). These colossal rates indicate the need for targeted support and advocacy for the prevention of adverse circumstances for individuals within services and beyond.

Epidemiological studies also reveal disproportionate prescribing of psychotropic drugs compared to other people, often without clear indication and with little evidence of efficacy (Ji & Findling, 2016; Sheehan et al., 2015). Such findings likely link to the historical institutionalisation and medicalisation of people with learning disabilities, where biomedical models of disability ultimately dehumanised people (Barden et al., 2022; Jarrett & Tilley, 2022). Comparatively, the past few decades have seen efforts to ensure support services are based on principles of empowerment, underpinned by the social model of disability (Hayes & Hannold, 2007). In contrast to a biomedical focus on what is ‘wrong’ with a person, social models acknowledge people’s impairments and differences, but highlight that social and political contexts cause the ‘disability’, discrimination, and much of the resultant harm (Gillman et al., 2000; M. Oliver, 2013). Learning disability services underpinned by such philosophies strive to put the person at the centre of their care, enable individuals to have choice over their support, and protect their rights to be treated as equal human beings (Whaley et al., 2018).

Promisingly, there is increasing movement towards such humanising approaches to support, such as person-centred care, and away from medicalisation (Perera & Courtenay, 2018). This culture shift is embodied by various ‘transforming care’ initiatives (Department of Health (DoH), 2012), brought about following the Winterbourne View scandal which discovered systematic abuse of people with learning disabilities in a specialist hospital for ‘challenging behaviour’ (Bubb, 2014). Relatedly, the past decades have seen a move towards recognising behaviours that others find challenging (hereafter termed ‘behaviours that challenge’) as a person’s way of communicating unmet needs and distress (Hastings & Brown, 2000). Thus, promoting the use of positive behaviour support (PBS) approaches (PBS Coalition, 2015) over psychotropic medications (Gore et al., 2013), in line with the related initiative of ‘stopping the over-medication of people with learning disabilities’

(STOMP; Branford et al., 2018a). However, there have been problems with implementing this transformation of care (Sinclair, 2018), which is failing to deliver main aims such as preventing systemic abuse and investing in community services to fully adopt person-centred care (J. L. Taylor, 2019). It has been suggested that most impediments to embracing various initiatives relate to power imbalances between learning disability services and those served (Whaley et al., 2018), thus perpetuating the disempowerment experienced by people with learning disabilities.

More recently, 'trauma-informed care' (TIC; Harris & Fallot, 2001) has offered promise in delivering services that adopt a sensitive, informed, and responsive approach to 'trauma', acknowledging that many individuals have experienced psychosocial adversity. It has been proposed that TIC can enhance person-centred care by promoting collaboration between care providers and people who use services (Bassuk et al., 2017) and thus shift the imbalance of power. Therefore, TIC is beginning to be embedded in learning disability services to enhance transforming care initiatives (Ferris-Rogers et al., 2021). However, it has been suggested that services still focus on altering individuals' responses to traumatic experiences, rather than focusing on the systemic causes of distress (G. Collins et al., 2022a). Thus, there remains a need for services to identify, address, and prevent oppressive circumstances which extensively impact people with learning disabilities. Accordingly, and dovetailing with TIC, the innovative 'power threat meaning framework' is gaining attention as a complementary approach that has potential to tie together these overarching philosophies (Hamer et al., 2022). That is, there is likely benefit in a framework that combines and brings forth principles of the social model of disability, person-centred care, and TIC to enhance the implementation of transforming care within learning disability services.

The power threat meaning framework (PTMF; Johnstone & Boyle, 2018) was developed as a way of conceptualising people's life experiences and helping to create more humanistic and hopeful narratives about their lives and difficulties they have faced or are still facing. Published by the Division of Clinical Psychology (DCP) and British Psychological Society (BPS) in 2018, the framework represents a five-year co-produced project linking evidence between social inequalities and adversity, including abuse and oppression, with psychological distress. The PTMF focuses on the role of *power* in people's lives, the *threat* that misuses of power pose, and the way someone has learnt to respond to such threats with threat-responses, which depends on the individual *meaning* attributed to the threats (Boyle, 2022; Cromby, 2022). Thus, the PTMF encourages reframing the question 'what is wrong with you?' to 'what has happened to you?' to centre how power has operated in people's lives. The framework consists of the following interrelated questions to develop a narrative style formulation; 'How did this affect you?', 'What sense did you make of it?', 'What did you have to do to survive?', 'What are your strengths?', and 'What is your story?'. General patterns summarising common ways of responding to power are offered for people to consider how their unique experiences fit and differ (Johnstone, 2022). It has been emphasised that the PTMF – unlike the dominant medical model – is offered as an optional conceptual resource and perspective to run alongside mainstream models and/or encourage thinking about alternative ways of working within current services (Johnstone et al., 2019). Though these conceptual ideas are not without debate and critique among mainstream psychiatry (Morgan, 2023; Rashed, 2023) nor are they proposed as fixed or universal (Johnstone et al., 2019). However, the PTMF has received criticism and been interpreted as 'extremist', 'polemical', and dismissive of the importance of psychiatric diagnosis for some individuals (Johnstone et al., 2019). Thus, highlighting the need to further explore the conceptual fit and relevance for different groups, including what PTMF concepts look like in practice.

The PTMF contains a specific sub-pattern for people with learning disabilities entitled 'being identified / identifying as having an intellectual disability' (Johnstone and Boyle, 2018, p. 224). Though, as predominantly developed in general adult mental health contexts, the PTMF concepts may require further interpretation and development to consider the specific experiences of people diagnosed with learning disabilities (G. Collins et al., 2022a). Thus, G. Collins et al. (2022b) recently developed a PTMF guide for people involved in providing support to outline and consider the operations of power that exist in the lives of people with learning disabilities and the possible impacts. The guide illustrates specific ways that the PTMF concepts relate to and can help to understand the experiences of this group, an example is provided in Table 1. Corresponding examples of powerlessness are documented within the literature, for example in relation to parenting (Franklin et al., 2022), disparities during the recent COVID-19 pandemic (Courtenay & Perera, 2020; Navas et al., 2021), and experiences of abuse by carers (J. Collins & Murphy, 2022). The PTMF posits that such threats to an individual's core human needs are coped with and survived via threat responses, such as behaviours that challenge which are a common reason for referrals to learning disability services. Thus, the PTMF has been proposed to hold promise as a non-pathologising framework to consider psychological distress and address related oppressive circumstances in the lives of people with learning disabilities (G. Collins et al., 2022a; Flynn & Polak, 2019).

Table 1

An Outline of the PTMF in Relation to People with Learning Disabilities using Examples from G. Collins et al.'s (2022b) PTMF Guide for People Involved in Providing Support

PTMF construct / formulation question(s)	*Power* What has happened to this person? How has power operated in their life?	*Threat* How has it affected the person? What kind of threats have been posed?	*Meaning* What sense might person have made of this? What is the meaning of the experience?	*Threat-response* What has person done to survive? What threat responses have they used?	*Strengths* What are the person's strengths? What access to power resources do they have?
Explanation	This question explores the adversities people have experienced and links negative operations of power to distress and behaviours that challenge	This part considers how negative operations of power can bring about difficult and threatening situations for people	The framework suggests how people respond to such treats depends on the meanings they make	The emotional, behavioural responses to threats, including unusual experiences, that we use to survive and/or reduce the threat posed	The positive aspects of power and advantage that promote resilience and coping accessible to a person and their resultant strengths
Example	A person lacks opportunities and support to form meaningful relationships (interpersonal power) and	The person experiences rejection when seeking relationships and encounters threats to feeling	The person may come to feel defective, rejected, unlovable, shamed and like	To preserve their identity and self-esteem, person may deny distress and instead act aggressively to	The person wishes to have caring and reciprocal relationships, is deeply caring and sensitive to the needs of others

	experiences difficulties with social skills (biological/ embodied power)	loved and does not feel valued by others, threatening their sense of identity	they are an inferior person	protect from feeling unloved To protect against attachment hurt, person may reject others	and has a good sense of humour

The application of the PTMF in practice and associated research is in its infancy, thus the framework is in the early stages of accruing an evidence base for clinical practice. Though documented uses of the PTMF are rapidly emerging in various applied settings, such as self-help peer led groups (Griffiths, 2019; SHIFT Recovery Community, 2022), youth mental health (Aherne et al., 2019), prison populations (Reis et al., 2019), adult mental health (Bostock & Armstrong, 2019), and the education of mental health professionals (H. Griffiths & Baty, 2019). The PTMF is also being applied in research contexts as a framework to conceptualise the experiences of participants from disempowered populations (Enlander et al., 2022; Leeming et al., 2022). Preliminary anecdotal feedback from professionals within adult mental health settings suggests that the PTMF enhances understanding, collaboration, and facilitates the implementation of TIC (Mitchell & Thorne, 2019; Nikopaschos & Burrell, 2020). A recent qualitative study similarly explored clinical psychologists' experiences of using the PTMF in such settings (Travers, 2022). Findings suggested that the PTMF was valued and may enhance sense-making, though systemic change is needed to implement the framework due to challenges navigating existing service structures. Whilst some of these experiences are likely to be relatable across settings, learning disability services are recognised as distinct from adult mental health services (Slevin et al., 2008). Thus, to what extent the PTMF is being applied in learning disability services and the experiences of professionals using the framework in this setting remain unclear.

One paper has described initial applications of the PTMF in an autism and learning disability service (Flynn & Polak, 2019). Authors concluded that the PTMF was a helpful meaning making tool to contextualise individuals' experiences, though the paper focused primarily on working with autistic individuals. More recently, a case study reported the use of a PTMF formulation with a black man diagnosed with schizophrenia and a learning disability (Beckles & Bush, 2022). The author posited that the PTMF provided an empathetic and anti-racist understanding of the client, and rather than being labelled a ‘schizophrenic’, the PTMF general pattern allowed the client and others to understand that he is a racialised man who is ‘surviving social exclusion, shame, and coercive power’ (Johnstone, 2022; p.21). However, these are the only known documented uses of the PTMF in the context of working with people with learning disabilities to date. Hence, there is no rigorous empirical research and consequently little is known regarding the practical applicability of the PTMF in learning disability contexts despite the proposed conceptual relevance (G. Collins et al., 2022a). Therefore, research is required to establish how the PTMF is being applied to working with people with learning disabilities, and what the strengths and limitations of the PTMF are for this population. This will help to clarify whether the PTMF could be used to support people with learning disabilities and in what ways, whilst highlighting further developments that may be needed to do so. Given the lack of research, exploring the application of the PTMF in learning disability contexts from the perspectives of professionals was considered an essential first step to empirically investigating this area.

Accordingly, the aims of this study were to provide novel insight into the applicability of the PTMF for adults with learning disabilities and their systems from professionals’ experiences, and to develop an understanding of professionals’ perspectives on the opportunities and challenges of the PTMF for this population in a UK service context. Thus, addressing the identified knowledge gaps to inform clinical implications and future research regarding the PTMF specifically for adult learning disability settings. The precise research questions for exploration were, ‘What are professionals’ perspectives and experiences of the actual and potential applications of the PTMF for adults with learning disabilities and their systems?’ and ‘What do professionals perceive to be the opportunities and challenges of drawing on the PTMF within adult learning disability services?’.

Methods

Design

A qualitative method was employed using semi-structured interviews and reflexive thematic analysis (RTA; Braun & Clarke, 2021c) to facilitate an in-depth exploration of eight psychological professionals' perspectives on, and experiences of, drawing on the PTMF in their work within learning disability services.

Choice of Methodology and Rationale

In line with the exploratory nature of this research, a qualitative design known as 'Big Q' (Kidder & Fine, 1987) was chosen. Qualitative research enables the exploration of participants' thoughts and emotions, facilitating a rich interpretation of the meanings attached to their experiences compared to quantitative approaches (Sutton & Austin, 2015). Thus, this approach allows for an in-depth examination of professionals' perspectives and experiences, while also acknowledging variability and nuance in how the PTMF may have been reviewed, understood, applied, and reflected upon. Importantly, the current study is rooted in qualitative research values and philosophical positions, which distinguishes 'Big Q' from 'small q' research methodologies (Kidder & Fine, 1987).

The study drew upon Braun and Clarke's reflexive approach to thematic analysis (TA; Braun & Clarke, 2021c) and the associated six-phase analytic process (Braun & Clarke, 2006, 2012). In terms of rationale, RTA was deemed the most complementary approach for the study aims and most fitting to address the research questions as it offers a theoretically flexible and more inductive orientation to TA (Braun & Clarke, 2021a, 2021b). Other qualitative methods of analysis were considered, though as the research questions do not aim to develop a theory, and focus on patterned meanings across participants rather than an idiographic focus, grounded theory and interpretive phenomenological analysis were deemed unsuitable (Braun & Clarke, 2021a). Similarly, RTA was chosen over narrative analysis as it allows for interpretating various shared patterns of meaning, rather than focusing on narrative accounts of personal experiences (Oliver, 1998). A reflexive approach was chosen as it closely aligns with the Big Q qualitative values that underpin this research (Braun & Clarke, 2022a). More specifically, and captured by the name reflexive, this method of TA emphasises that knowledge is not independent of those who produce it (Braun & Clarke, 2022a). Thus allowing the researcher to take an active role in the production of knowledge via subjective engagement throughout the research process (Braun & Clarke, 2019). Therefore, it is inevitable that a researcher's philosophical and theoretical assumptions inform the research, and thus important to explicitly consider these positions early on (Willig, 2013).

Research Values and Theoretical Basis

The current study is underpinned by a critical realist ontological and epistemological position. Often referred to as a weaker form of constructivism (Sayer, 1997), critical realism emphasises that humans are meaning-making beings who construe and co-construe a separate and everchanging reality (Archer et al., 2013). That is, alike constructivist postulations, people, including researchers, construct knowledge based on their perceptions of the world, which are influenced by their position in it and past experiences (Hofer & Pintrich, 2004). Arguably in its development, the authors of the PTMF were influenced by similar anti-positivist ideologies (Pilgrim, 2022), discordant with positivist paradigms which posit reality can be measured via objective science to uncover universal truths (J. Martin, 2003). Thus, critical realism is in keeping with the theoretical concepts underpinning the PTMF (Cromby, 2022; Pilgrim, 2022), as well as the researchers' fluid position between constructivism and post-positivism.

Reflexivity

The researcher's personal and professional perspectives cannot, and arguably should not (Braun & Clarke, 2022a, 2022b) be separated from the processes within qualitative methods such as RTA (R. Elliott et al., 1999). Instead, researcher subjectivity is considered a tool and resource in the current study (Gough & Madill, 2012). To embody this, the researcher reflected on their own values, social and professional standpoints, and positionings as they emerged throughout the research process using a reflective journal (excerpt displayed in Appendix A).

In addition, transparently owning one’s perspectives as the researcher is important for the reader to understand the lens through which the research has been conducted and embrace the subjectivities the researcher brings to the process (Braun & Clarke, 2021b; Yardley, 2017). As the lead researcher, I am a white female trainee clinical psychologist with keen interests in psychological formulation, social justice, and advocacy. I do not have any close personal relationships with anyone with a learning disability, and thus my experiences of meeting people are purely from a professional position. Whilst designing and developing the research I worked within an integrated adult learning disability service in London. I observed a tendency for systems to pathologise the emotional distress people I met were experiencing and expressing, though I believed such responses were likely understandable considering their often-unexplored context. As I began to gently advocate for a focus on ‘what has happened to this person?’, I developed a particular interest in the uses and abuses of power in the lives of, and services supporting, people with learning disabilities and social discourses around (dis)ability. Whilst I would not identify that I explicitly drew on the PTMF in this work, I had some conceptual understanding of the PTMF and began to consider how it may apply to the experiences of people with learning disabilities prior to commencing the research. Importantly, I recognise the complexity around the diagnostic debate, being re-traumatising for some whilst containing for others, and currently providing access to services for all. Though I am aware that I bring a professional preference for empowering people to identify in whichever way they find most meaningful and a personal preference for psychosocial understandings rather than diagnostic perspectives. Lastly, I did not intend to explore the diagnostic debate in this research but more openly how the PTMF may be implemented, with a focus on the PTMF as a formulation framework.

Ethics

Ethical approval was obtained on 24 May 2022 through Royal Holloway University of London Research Ethics Committee (Appendix B). In order to uphold respect for participants, each participant gave written informed consent and was reminded of their right to withdraw (R. Elliott et al., 1999). No instances of risk arose during the research process.

Participants

The total sample comprised of eight participants, five females and three males, with an average age of 45 years old (range 27-58 years). Six participants identified their ethnicity as White British, one as Black Bermudian, and one as White Other. Participants had an average of 19 years' experience working with adults with learning disabilities (range 1.5 – 32 years) and 30 months of experience drawing on the PTMF in their work (range 4 – 60 months). The participants were all from a psychological professional background, with a range of experiences and varying levels of education. Further information related to participants' professional backgrounds is presented in Table 2 to describe the sample and thus allow for the reader to consider the characteristics of the sample (R. Elliott et al., 1999).

The inclusion criteria for the study were any professional working in the UK to support the mental health and wellbeing of adults with learning disabilities. Participants had to be either currently working in a relevant role or to have been within the last six months. Participants had to be able to identify that they were either currently using the PTMF in their work, or had historically used, or tried to use, the PTMF in their work if they did not currently. Lastly, participants needed to be sufficiently familiar with the PTMF, which here required participants to self-report experience of drawing on the PTMF to inform at least one clear area of clinical practice, be able to identify at least four of the six main PTMF questions, and have attended at least one PTMF presentation or read one of the official PTMF documents.

Table 2

Participants' Professional Background Information

Participant	Profession	Highest level of education	Current role and banding	Current service type	Previous relevant services	Experience in adult LD services	Experience drawing on PTMF
1	Clinical Psychologist	Doctorate	Principal Clinical Psychologist (Band 8b)	NHS community and inpatient LD service	N/A	8 years	8 months
2	Clinical Psychologist	Doctorate	Clinical Psychologist (Band 8a)	NHS eating disorder service but most recently NHS community LD service	Self-advocacy services for people described as having a learning disability	20 years	60 months
3	Clinical Psychologist	Doctorate	Consultant Clinical Psychologist (Band 8c)	NHS community LD service	NHS community LD service, assessment and treatment unit, inpatient forensic LD service	15 years	36 months
4	Clinical Psychologist	BSc degree	Psychology Practitioner (N/A)	NHS community LD service	Manager of supported housing services	30 years	24 months
5	Clinical Psychologist	Doctorate	Consultant Clinical Psychologist (Band 8c)	NHS community LD service	NHS inpatient LD service	32 years	12 months
6	Trainee Clinical Psychologist	MSc degree	Trainee Clinical Psychologist (Band 6)	NHS adult secondary care psychological service	NHS community LD service	1.5 years	4 months
7	Professor and Honorary Consultant Clinical Psychologist	PhD	Clinical Academic (N/A)	NHS inpatient LD and autism service	Social care, NHS community LD service, assessment and treatment unit, forensic medium-secure LD service	24 years	48 months
8	Clinical Psychologist	Doctorate	Consultant Clinical Psychologist (Band 8c)	NHS community LD service	Children with LD, Asperger diagnostic service, social care specialist assessment service for parents with LD	21 years	48 months

Note. This table uses 'LD' and 'LD service' as abbreviations used to term UK NHS learning disability services and in line with information provided by participants.

Recruitment

A nationwide recruitment strategy was utilised as the PTMF is not currently widely adopted, particularly with people with learning disabilities, therefore the sample of professionals familiar with and drawing on the framework in this context was anticipated to be limited. Research advertisements (Appendix C) were posted on professional social media networking platforms, such as Twitter and Facebook groups. In addition, the recruitment advert was circulated amongst the BPS and DCP Faculty for People with Intellectual Disabilities emailing list and posted on The UK Health and Learning Disabilities Network website. Purposive sampling was utilised to ensure participants met the inclusion criteria, specifically in relation to their level of experience and familiarity with the PTMF. A brief screening questionnaire was devised to check eligibility of prospective participants (Appendix D).

Materials

The study utilised semi-structured interviews as the method for data collection, whereby participants were encouraged to take a lead in guiding the conversation based on their unique accounts, which is in keeping with RTA (Braun & Clarke, 2022a) and a truly exploratory approach (Willig & Rogers, 2017). Data quality was thoughtfully considered in the design process, with a goal to prioritise a flexible and fluid interview style to gain in-depth accounts of each participant's unique experiences and perspectives.

The semi-structured interview schedule (Appendix E) was developed in line with the study aims and research questions. Consultation with two clinical psychologists in the field, who form part of a working group for the PTMF and people with learning disabilities, informed the content of the schedule to optimise data relevance and quality. The topics for exploration were carefully considered and related questions with prompts organised to allow the researcher to respond flexibly to participants' responses. The schedule was piloted with a member of the working group, which led to certain questions being reworded to enhance clarity and encourage lifelike, free flowing, and detailed conversations around issues relevant to the research questions (Braun & Clarke, 2022a).

Procedure

All participants contacted the lead researcher via email to express interest in response to recruitment adverts. They were sent an information sheet (Appendix F) and invited to arrange a convenient time for a brief five-to-ten-minute screening telephone call if they wanted to participate in the research. During this call, the researcher reviewed the eligibility screening questionnaire, discussed the information sheet, and answered any questions about the study. If participants met eligibility criteria and wished to take part, a time for the virtual interview session was arranged and participants were emailed a consent form to review and return (Appendix G). This email also contained a link to a demographic questionnaire on Qualtrics (Appendix H) and participants were asked to complete this before the interview session.

Interviews were conducted over MS Teams video conferencing software, and both recorded and transcribed live using the MS Teams recording and transcription services. The participants were asked about their experiences of, and perspectives on, drawing on the PTMF in their work with adults with ID, loosely guided by the interview schedule, which was sent to participants via the chat function. This allowed for weaving flexibly between different parts of the schedule so that discussions were guided by what appeared most meaningful for the interviewee. Once the interview came to a natural close, the participants were debriefed and thanked for their time. All participants agreed to be contacted during analysis to review and provide reflections on the thematic map. Interviews took place from September to December 2022 and lasted between 53 and 91 minutes ($M = 69.63$).

All interviews were transcribed verbatim, using the transcribed interview files provided by MS Teams transcription service as a template whilst listening back to each recording to check accuracy and correct errors for the exact replication of the audio recorded interviews. All identifiable information was anonymised or omitted, and interview recordings were deleted following transcription.

Analysis

Braun and Clarke (2021c) offer a systematic yet flexible six-phase process for undertaking RTA, which was engaged with in a dynamic manner (Braun & Clarke, 2019). Table 3 outlines a descriptive account of the specific approach to RTA taken by the researcher (Trainor & Bundon, 2021). Notably, a more inductive approach to analysis was taken due to the exploratory aims of the study and lack of existing theoretical constructs regarding PTMF and learning disability contexts.

Table 3

Process of Reflexive Thematic Analysis Undertaken (based on Braun & Clarke, 2021c)

Phase of analysis	Description of process undertaken
Phase 1: Familiarisation	Following transcription, each recording was actively listened to once more before closely reading and re-reading the entire dataset. Familiarisation notes of potentially interesting passages and initial trends across the dataset, as well as the researchers' reflections on these, were documented (extract presented in Appendix I).
Phase 2: Coding	A systematic approach to coding was adopted, giving equal consideration to each data item to rigorously interpret patterns of meaning relevant to the research questions. This process was repeated twice; the first stage was completed in chronological order of transcripts on Microsoft Word using comment function. Appendix J demonstrates an example extract of coded data. Coding from three transcripts was reviewed with supervisor and alternative interpretations of the data were reflected upon. The dataset was then transferred to Nvivo 12 for a second stage of coding transcripts in randomised order. Codes were generated at both a semantic and latent level.
Phase 3: Generating initial themes	Codes were organised into initial clusters of shared meaning in Nvivo 12 to generate candidate themes. Particularly salient codes were made into potential themes, whilst other themes and subthemes were generated by interpreting patterns of shared meaning across codes. All codes were considered during this process, and codes interpreted as not fitting within this initial analysis were kept aside for consideration as the analysis evolved.
Phase 4: Reviewing potential themes	Initial themes and subthemes were visually mapped to consider how each theme could contribute to tell an interpretive story of the data to address the research questions (Appendix K). Recursive re-engagement with coded data extracts and overall dataset allowed the researcher to develop the richness of themes, review their fit and distinctiveness. Potential themes and subthemes were reviewed with research supervisor to finalise a draft thematic map. A draft table of themes (Appendix L) was emailed to all participants inviting them to provide member reflections (Appendix M). The draft themes were also discussed with the consulting advisory professional stakeholder to further review draft themes.
Phase 5: Defining and naming themes	To finalise the thematic story, member reflections were contemplated to elaborate the interpretation of each theme and subthemes. Naming themes involved using salient quotes from participants that related to the central organising concept of each theme.
Phase 6: Producing the report	An analytic narrative was developed by interpretively expanding on themes and subthemes alongside quotations from interviews to illustrate the analytic story and contextualise the analysis. Member reflections were incorporated and held in mind.

Rigour and Quality Assurance

In accordance with guidance on RTA, the subjectivity of the researcher was integral to the analytic process and thus quality assurance addressed the rigour of the method, rather than the accuracy or objectivity of the analysis (Terry & Hayfield, 2020). In keeping with contemporary ideas around quality assurance for RTA (Braun & Clarke, 2021b, 2022b), the analysis process was engaged with thoroughly as described in Table 2, including ongoing reflection of code and theme development with the research supervisor. Moreover, Braun and Clarke's (2021b, p. 345) 20 critical questions to promote high standards in RTA research were adhered to, such as situating the analysis within a theoretical context by outlining the underlying research values and philosophical positioning. Ultimately, the researcher endeavoured to own their personal and theoretical perspectives, be purposeful in decision-making processes, and reflexive throughout to become a 'knowing' RTA researcher (Braun & Clarke, 2022b).

In addition, and consistent with traditional guidance for high quality qualitative research (R. Elliott et al., 1999), quotations are presented throughout the results to enhance transparency of interpretation and descriptive data is provided for readers to contextualise the findings. As a big Q alternative to conventional credibility checks (R. Elliott et al., 1999), 'member reflections' were utilised instead of member checking to more closely align with the RTA approach (Braun & Clarke, 2021b, 2022b; Tracy, 2010). That is, instead of focusing on participants' validation of the findings, member reflections were sought for reflexive elaboration of the results (Braun & Clarke, 2021c), including whether they felt the results were comprehendible, meaningful, or objectionable based on their participation. Five participants provided their reflections on the draft results (Appendix N), which mostly expressed close resonance with the interpreted themes and an enthusiasm for the analytic output. Participants' reflective comments relating to how certain themes fitted or differed to their conviction behind the pattern of meaning were used to finalise themes and held in mind when creating the report. Thus, member reflections facilitated further reflection on how such nuances within themes were reflected in the report and enriched interpretation of the results (Smith & McGannon, 2018).

Results

The following four themes were generated through the analysis: (1) “Raising the flag” for PTMF and People with Learning Disabilities, (2) Enhancing by Asking, “What’s happened to this Person?”, (3) PTMF as a “System-wide Approach”, and (4) “There’s still a way to go” for PTMF in Learning Disability Contexts (and beyond). Themes will be descriptively outlined in turn, using direct quotations from participants alongside the researcher’s analytic narrative. Following this, an overall interpreted story of the data and associated thematic map (Figure 1) are presented. Table 4 displays the generated themes and related subthemes, along with which participants contributed to each, to further enhance transparency.

Table 4

Table of Themes and Subthemes with Corresponding Contributing Participants

Theme	Subtheme	Contributing participants							
		Ppt 1	Ppt 2	Ppt 3	Ppt 4	Ppt 5	Ppt 6	Ppt 7	Ppt 8
"Raising the flag" for PTMF and People with Learning Disabilities	People with learning disabilities are disproportionately disempowered	✓	✓	✓	✓	✓	✓	✓	✓
	Re-articulates and validates influential ideas	✓	✓	✓	✓	✓	✓	✓	✓
	Re-humanises psychiatric diagnoses	✓	✓	✓	✓	✓	✓	✓	✓
Enhancing by Asking, "What's happened to this person?"	Tending to power imbalances	✓	✓	✓	✓	✓	✓	✓	✓
	Developing deeper understanding of context and enhancing compassion	✓	✓	✓	✓	✓	✓	✓	✓
	Enhancing neurodiversity diagnostic frameworks	✓	✓	✓	✓		✓	✓	✓
PTMF as a "System-wide Approach"	A wider scope than direct therapy	✓	✓	✓	✓	✓	✓	✓	✓
	PTMF applies to everyone	✓	✓	✓	✓		✓		✓
	Opportunities for PTMF as a trauma-informed service delivery model	✓	✓	✓	✓	✓	✓		✓
"There's still a way to go" for PTMF in Learning Disability Contexts (and beyond)	PTMF is at odds with current NHS service systems	✓	✓	✓	✓		✓	✓	✓
	Navigating power when sharing PTMF ideas	✓	✓	✓				✓	✓

Theme 1: "Raising the flag" for PTMF and People with Learning Disabilities

The first theme illustrates a collective sense expressed by participants that conceptually the PTMF *"fits completely" (Ppt 2)* and is *"massively relevant" (Ppt 8)* for people with learning disabilities, and so *"raising the flag" (Ppt 5)* for PTMF within learning disability contexts is important. This theme comprised three subthemes: (1.1) people with learning disabilities are disproportionately disempowered, (1.2) PTMF re-articulates and validates influential ideas, and (1.3) re-humanising diagnostic frameworks, all three of which were thought to represent varied manifestations of participants perceptions related to how the PTMF fits conceptually for people with learning disabilities and why it is important within such contexts.

1.1 People with learning disabilities are disproportionately disempowered

That the PTMF is particularly relevant for people with learning disabilities was largely interpreted from participants consistently recognising that such individuals are one of the most disempowered groups in society, that is *"there are very few groups where that is just so overtly, that power, is a problem all the time in every aspect of that person's life" (Ppt 2)*. Participants highlighted examples of interpersonal powerlessness, suggesting a significance of relational power ideas posited by the PTMF:

> *"It's massively relevant, isn't it? Because people with learning disabilities are already in a kind of disempowered position and are massively reliant on others in their lives to make sure, to care for them. And those care relationships are inherently, the power in those relationships because of the cognitive impairment, are inherently disproportionate." (Ppt 8)*
>
> *"People with learning disabilities are at an inherent disadvantage because they often are reliant on others in order to be able to access certain bits of our society, but that brings with it an inherent vulnerability and that therefore brings them perhaps a little bit closer to being at risk of exploitation, bullying, abuse, malpractice." (Ppt 7)*

Participants' repeated use of words like 'inherent' implied that negative operations of power are pervasive experiences for people with learning disabilities, and alongside explicit references suggested a particular relevance of the PTMF, because they are "*some of the least empowered people that we might be working with" (Ppt 3).* All participants spoke of a strong conceptual fit and proposed the PTMF may even be, *"more important for people who are described as having an intellectual disability because they have even more power imbalances and they've got a higher* *chance of being oppressed and so it's really easy to see how it applies to people with learning disabilities" (Ppt 2).*

1.2 Re-articulates and validates influential ideas

Participants noted that the PTMF especially fits as it overlaps with, and re-articulates, existing influential conceptual ideas such as *"formulating from a social model of disability" (Ppt 6)*. Participants described a sense that the PTMF "*articulates or rearticulates [these ideas], and packs them up into, 'don't forget about this, this is very important', because of course sometimes that can happen" (Ppt 7).* Linked with this, some participants reflected that the PTMF has validated their preferred ways of understanding and working with people with learning disabilities, which are not always promoted in services. For example, one participant described a sense of excitement hearing of the PTMF "*because it felt like the kind of ways I work in learning disabilities were being more validated. That it's more individual formulation led, and recognises complexity" (Ppt 8)*, whilst another reflected that:

> *"I was really excited by the development of it, because I think when you think about power all the time, when you're thinking in a sort of constructionist way, you can't not think in that way, but you also feel very alone when people talk as if other things are truths around you, that often feel they are to support those in power rather than the people we work with." (Ppt. 2)*

These expressions of excitement were thought to symbolise participants' enthusiasm for the PTMF in putting new language to existing ways of thinking, to validate practicing in such ways, and to ensure these ideas are considered and not forgotten.

1.3 Re-humanises psychiatric diagnoses

The perceived conceptual fit of the PTMF was further inferred from participants spontaneously acknowledging the shortcomings of psychiatric diagnoses in understanding emotional and behavioural distress of people with learning disabilities. Most participants expressed that they wished to avoid *"reducing people down to a diagnosis" (Ppt 5)* and "*imposing symptom-based models on people that don't fully fit and further perpetuate the power difference in their lives" (Ppt*

2). This indicated that participants felt diagnoses alone fail to meaningfully understand individuals' experiences, supported by the concern that diagnostic labels *"miss a lot of the real life of people with LD and understanding people's adversities" (Ppt 1)* and can be unhelpful, "*it's interesting to me how often behaviour now it's 'Ohh, it must be bipolar, it must be depression, it must be anxiety… give them a tablet' … It's just not helpful, is it?" (Ppt 4)*. Multiple participants perceived problems with psychiatric medications being prescribed when individuals' experiences and behaviour were poorly understood:

> *"There was a client who was given a diagnosis of it might have been psychotic depression, or it might have been bipolar, anyway, he was put on lithium. And I'm just like, hang on a minute! Look at all these things that have happened to this young person?! Look at how this member of staff has kind of been drawn into, I think a projective process with this client. The client was the one who was arrested, the client was the one who had to move, the client is the one who gets pathologised and medicated. This isn't OK to wrap this up as a mental health problem and give somebody lithium! It's entirely understandable that this young man with a learning disability and autism is going to respond in these ways to people who interact with him in these ways." (Ppt 3)*

Taken together, participants highlighted that the PTMF *"fits much better" (Ppt 5)* than psychiatric frameworks and represents an important set of ideas that re-humanise how we understand people with learning disabilities and experiences of psychological distress.

Theme 2: Enhancing by Asking, "What's happened to this person?"

Most participants referenced drawing on PTMF core questions, such as 'what's happened to this person?', to enhance team formulations with multi-disciplinary teams (MDTs) and care staff. The PTMF appeared to be particularly helpful in enhancing systems' understanding of behaviours that challenge, relational difficulties, and neurodiversity traits. Notably, participants emphasised that they draw on the PTMF in a complementary manner, to enhance rather than replace existing ways of working, summarised by one participant:

> *"I don't use it [PTMF] in and of itself, it's an enhancement to me. It has added that like more breadth to our understanding … and allows for that wider thinking around somebody's circumstances and what other adversities they might be going through that we might ordinarily just discount or not bring to our conscious." (Ppt 1)*

This theme, consisting of three subthemes, encapsulates a salient pattern of meaning interpreted from participants' accounts of drawing on the PTMF to enhance existing ways of working through: (2.1) tending to power imbalances, (2.2) developing deeper understanding of context and enhancing compassion, and (2.3) enhancing neurodiversity diagnostic frameworks.

2.1 Tending to power imbalances

There appeared to be a focus on the power part of the PTMF, with participants utilising and appreciating the PTMF as a tool to explicitly tend to power imbalances, primarily in their work with systems around people with learning disabilities by considering *"who's got the power?" (Ppt 4).* The PTMF was described as enhancing existing ways of working by *"thinking very much about how the power part of things operates and kind of making that more visible, because that has a tendency to be overlooked" (Ppt 3)*, despite the interpreted relevance. One participant explained that existing models "*don't necessarily think so much about the previous sort of power imbalances and the existing ones, and people don't really want to concentrate on that" (Ppt 4)*. Thus, participants used PTMF ideas to bring power imbalances to systems' attention, such as supporting care staff to consider the positions of power they find themselves in when supporting people with LD:

> *"But power is very, particularly in learning disabilities, we have to remind people about who's got the power. I've been running a men's group for seven years and something that's upset me regularly, has been when we've said to the men in the group, who live in supported accommodation, if you had an argument with a support worker, could you be right, and they be wrong? And a lot of the time they said 'no, the support workers are always right'. Now that's quite disturbing to me because…and I fed that back to staff teams, because I think it's quite powerful to say, even though you mean well, you have this power all the time…even*

> *when you think you're acting in the best interest of somebody by encouraging them to make a decision in a particular direction. You still hold that power, and people are entitled to make bad decisions for themselves. And sometimes that's powerful in itself, just giving them the opportunity to do so. I think using that side of it [PTMF], is extremely important just to get people to think about who's got the power in this relationship." (Ppt 4)*

This connected to the interpreted disproportionate disempowerment of people with learning disabilities and importance of highlighting this within systems. One participant highlighted using the PTMF to attend to power in inpatient contexts, where the use of restrictions amplifies powerlessness, "*I was thinking hang on a minute, there's a lot of power imbalances here. We're making lots of decisions about people and how can we understand and how could I help the team understand, in the context of the PTMF" (Ppt 1)*.

In addition, participants spoke about using the PTMF to address power imbalances in the context of understanding and supporting behaviours that challenge, which was described to enhance existing models like PBS, as *"there's more thought about how their behaviour is presenting in relation to things that have happened to them, and places more emphasis on where power is. So, who's made those decisions for them and what does that mean for the individual?" (Ppt 4).* A couple of participants had drawn on the PTMF in direct therapeutic work and similarly focused on tending to power, "*I think it's particularly the power part, trying to illustrate systemic power, isn't it? It's kind of societal power…and trying to help him to see that, that they're the things that have happened to him, that weren't within his control" (Ppt 5)*. This emphasis on power offered by the PTMF was considered a novel enhancement by most participants, *"the power bit, I don't see in many other places, where it's emphasised, who's got the power, who's had the power, what does that mean? How threatening is that for people? I don't see that in any other models" (Ppt 4)*.

2.2 Developing deeper understanding of context and enhancing compassion

All participants articulated that drawing on the PTMF, via tending to power imbalances and what has happened to a person, develops a deeper understanding of people with learning disabilities by considering their social and historical context. Most participants focused on their experiences drawing on the PTMF systemically to enhance others' understanding in the context of behaviours that challenge, by considering behavioural responses in relation to psychological distress and what's happened to the person, both past and present:

> *"You know, trying to help others think about what else might be going on, or trying to contextualise something and broaden out that kind of perspective, and trying to kind of say, in a way to kind of normalise, well, of course this person's going to be feeling like this when this has happened. Or, if I were them, that's probably what I would do, you know?" (Ppt 3)*

> *"The most important thing is sharing background history … people get that moment of 'Gosh! Oh my gosh, that makes sense!', 'cause that can help make the link to what they're seeing now, rather than they are just a person who's engaging in this really awful thing." (Ppt 1)*

Participants frequently referenced that the PTMF *"fills the gaps in terms of context … that PBS alone does not" (Ppt 6)* and thus enhances and humanises the understanding of behaviours offered by PBS:

> *"I can honestly, truly say that where it's [PTMF] been so helpful is externalising the behaviours that challenge. I know PBS does that and brings challenging behaviour out of the interaction between a person and their environment, but it also comes out of their environment, and the history, the what's happened to them. And that was the bit that like I think really gets people to tap into, it's that real human experience that I think everyone can understand and really engage with and empathise with that can only ever support and enhance person-centred care." (Ppt 1)*

Ultimately, the PTMF was perceived to facilitate an enhanced understanding of individuals' emotional and behavioural distress by developing a deeper understanding of their context than existing models, such as PBS. In turn, this was thought to encourage a more compassionate and empathetic understanding of people with learning disabilities among their support systems:

> *"I think when you've got the PTMF, care staff can slot their ideas into the framework, and they get it, and you can say, if that was you, if you've had those same feelings of powerlessness … how would you try and influence them? And then you can see light bulbs going on and people say 'actually, I might do something similar'." (Ppt 4)*

Thus, enhanced compassion appeared to result from using the PTMF to normalise the responses of people with learning disabilities, allowing staff to *"put themselves into the shoes" (Ppt 1)* of the individuals they support, and realise their behaviour makes sense considering what has happened to them. Moreover, one participant described how drawing on PTMF core questions implicitly within direct therapy similarly allows for deeper consideration of context to foster compassion:

> *"It's a kind of like a walking, I call it walking alongside somebody. You know, the idea of kind of just walking the walk for a little bit and going, you've had a tough gig, you know, it's been difficult." (Ppt 5)*

Thus, participants' accounts of drawing on the PTMF were interpreted as describing a process of developing a deeper understanding of a person's context and resultantly enhancing compassion:

> "*Helping us to view it as these are adults who are trying to communicate distress in the only way they know how" (Ppt 6)*.

2.3 Enhancing neurodiversity diagnostic frameworks

Some participants proposed that the PTMF could be drawn on from a *"both-and" (Ppt 1)* perspective alongside neurodiversity diagnoses for people with learning disabilities. A few participants expressed concerns that positioning the PTMF as an alternative to neurodiversity diagnoses might be invalidating for individuals who identify as neurodiverse, with one participant warning, *"these diagnostic labels are often valued and have an inherent social value to individuals" (Ppt 7).* It appeared that this balance of drawing on the PTMF whilst appreciating the value neurodiversity diagnoses may have for people was a complex part of implementing the PTMF in learning disability contexts:

> *"But when we're talking about [PTMF] as an alternative to a diagnosis, things like neurodiversity diagnoses like ASD in particular, it could come unstuck because you don't want to give an impression that somebody's autism diagnosis is not valid. Whilst at the same time, I suppose it's about holding both-and isn't it?" (Ppt 1)*

Thus, some participants proposed drawing on the PTMF to enhance neurodiversity diagnoses by providing richer idiosyncratic understandings of an individual's experiences:

> *"I think there's a lot of crossover, especially with adults who are being diagnosed with autism later in their lives, where sometimes we'll have a question about some developmental trauma, or some other kind of attachment difficulties, that might be present, that again to not invalidate a diagnosis of autism, but that there are other things that are at play and we can maybe use the PTMF to support some of that understanding of what's going on." (Ppt 1)*

> *"We might think about things like why is the person doing that? If somebody's self-stimulating and even like using that language is not helpful, you kind of need to say well why? … But people don't do that, I think what people tend to do is say, why are they doing that? Well, it's cause they're autistic. You just get these circular arguments everywhere, and why are they autistic? Because they do that. Well, what's the internal experience of that person?" (Ppt 2)*

These insights suggest that expressions of distress can be attributed to neurodiversity diagnoses and consequently miss the unique experiences of the person, resulting in reductionist understandings of people. One participant suggested that ultimately, *"the things they talk about in the framework are really relevant, remarkably relevant, but they're complementary… They're helpful to be able to formulate an understanding [around diagnoses], to sometimes encourage a different way of working, I would suggest" (Ppt 7).*

Theme 3: PTMF as a "System-wide Approach"

The third theme reflects that the PTMF was considered a *"system-wide approach to thinking" (Ppt 1)* and thus perceived to be most relevant at a system-wide level in learning disability contexts. That is, as one participant summarised, *"it kind of feels like you want to see this [PTMF] in terms of whole system change, rather than an add-on" (Ppt 2).* Thus, participants were most commonly drawing on the ideas within systems, as the PTMF was perceived to be "*more about the system, because that's where the biggest power imbalance is" (Ppt 4)* and unless you consider the system, *"it's really difficult to support the individual" (Ppt 2)*. Three subthemes related to the sense that the PTMF is best considered and implemented as a system-wide approach: (3.1) a wider scope than direct therapy, (3.2) PTMF applies to everyone, and (3.3) opportunities for PTMF as a trauma-informed service delivery model.

3.1 A wider scope than direct therapy

Participants mostly spoke of their experiences drawing on the PTMF indirectly and systemically within learning disability contexts. Participants linked this to the nature of services and that "*a lot of our work as psychologists, especially in LD teams, is helping everyone else understand people from a different viewpoint, so it's thinking more about how we can influence the system to understand people from a different, from this [PTMF]" (Ppt 1)*. One participant shared that:

> *"There's a whole systemic layer of stuff that needs to happen around the PTMF … like the meaning question, I'm like well what about the meaning that everybody else in the system gives to this behaviour? … So, I think the scope of [PTMF] for applying it to people with intellectual disabilities needs to be a bit wider." (Ppt 3)*

Linked with this, participants acknowledged the systemic nature of working indirectly to support people with profound learning disabilities and when direct therapy drawing on the PTMF would not be accessible nor appropriate:

> *"[For some] you could literally from the get-go say, 'we're gonna use this framework, here's the template, here's the approach…', and they could probably engage in it on an intellectual level and cognitive level and emotional level. But there are others that probably it wouldn't work like that…However, we have the opportunity in learning disability services to work alongside carers and paid care staff and that's a lot of the indirect work that we do… so, how*

> *we could use the framework to help other people understand about their loved one or their client." (Ppt 5)*

This led participants to reflect on the limited utility of the PTMF for therapeutic work, particularly questioning the appropriateness of using the ideas directly when the PTMF highlights problematic systems of power:

> *"I'm very reluctant… and again I think probably a lot of the issues are that I would be reluctant to see that person for one-to-one work … If I thought the issues were wider and systemic, I would do something else rather than reinforce the idea that that person is the problem rather than the problem being the problem." (Ppt 3)*

In addition, participants felt that direct therapy wouldn't influence the system as needed, "*you could apply these [PTMF] ideas in your individual work, but to what extent does that influence how other people go about what they're doing?" (Ppt 2)* and ultimately "*gives the message that the person that needs to change is the person who's coming to therapy rather than looking at the wider social contexts" (Ppt 3)*. However, some participants described a tricky line whereby the PTMF could become exclusive if people with learning disabilities are not included and emphasised caution to not perpetuate the very thing the PTMF advocates against:

> *"Which is problematic because if, I think the PTMF is inherently kind of trying to use powers for good, but I think that's still inherently a problem … I'm not sharing the power with her to help herself … if things are still being done to a person there's still so many problems, that's the entire history of learning disabilities as being so patronising and paternalistic when these are adults that can do a lot of things for themselves, even if they need a little bit of help, not having things done for them all the time. So, we don't wanna perpetuate that, I think that's something to consider." (Ppt 6)*

3.2 PTMF applies to everyone

Participants often reflected that whilst drawing on the PTMF in team formulations it was helpful to consider everyone through the PTMF lens to emphasise that systems of power are pervasive and impact on us all. Participants highlighted that people (families, paid care staff and professionals) often experience parallel operations of power to the individuals they support, which the PTMF can emphasise:

> *"You're working in the power relations between a professional and a family member or a member of staff who might be being physically assaulted, and is understandably, they're going to be going through their whole own set of things about what's happening to them and what they understand of what's happening as well." (Ppt 3)*
>
> *"The PTMF, I really think the way in which we can use it enables us all to go, I'm feeling threatened, you're feeling…we all have these things! It's not about only like the one in four or them and us kind of, you know, model of thinking. It's just like every day in our lives there's power imbalances at play." (Ppt 1)*

Linked with this, participants described how the PTMF can be used to recognise the relational and interactional nature of providing and receiving care, and proves helpful to consider staff experiences and responses to situations:

> *"I do try and draw it out because I might go, well they're feeling, for example … like, rejected or frustrated and things like that. And I'll say, well, and how are we feeling at times? Like we're pushed away and rejected and frustrated and our threats and what are our responses and how those kinds of responses aren't helpful when they're interacting with one another." (Ppt 1)*

Similarly, participants described how drawing on the PTMF to consider staffs' experiences can help to create supportive environments in systems by asking, *"'Do you get support?' 'Do you get supervision?' 'Do you get clear directions on what you're supposed to be doing?' 'What's it like?' You know, 'Do you get enough rest between your shifts?' and all that kind of thing" (Ppt 4)*.

Additionally, participants highlighted that the PTMF importantly recognises services and professionals as part of the power imbalances faced by people with learning disabilities, *"when you're looking at power, we're in there, aren't we? … what it [PTMF] allows you to do is, talk about* *power, context, and include yourself, the services you work, your colleagues, and those parts of the person's context" (Ppt 2)*. Further emphasising that the PTMF considers power within and across systems, and so is best applied at a system-wide level.

3.3 Opportunities for PTMF as a trauma-informed service delivery model

Participants proposed opportunities for the PTMF to be implemented at a service level within learning disability services, further promoting a system-wide approach. This stemmed from participants identifying that *"there does need to be a bit of a paradigm shift in how we understand and deliver mental health services" (Ppt 3)* and the PTMF supports this *"move away from a psychiatric 'what's wrong with you' framework and fits nicely with a trauma-informed care approach" (Ppt 5)*. Many participants spoke of the overlap with TIC and suggested the PTMF "*provides a framework to have those trauma-informed discussions" (Ppt 1)* and thus supports the implementation of TIC.

Participants offered hypothetical ideas for using the PTMF more widely within services based on their experiences, *"I'm sort of thinking the language of the PTMF and those ideas, I can think of loads of ways they could be used as a whole service … I think it has to be at that level and then look at the outcomes for people" (Ppt 2)*. One participant described their contemplation around utilising the PTMF to guide service-delivery by enhancing understandings of individuals when they first meet with services:

> *"What I'm thinking in terms of literally a framework, is using the PTMF as a way of helping us to understand and helping other people to understand what's happened to somebody that brings them into the service … So how do you get a broad brush? How do you get something that's broad enough to help us to understand what we need to do next, but isn't specific that means that people are excluded? ... This framework, you see, I think lends itself perfectly to that initial, let's understand better about what's happened to somebody and then we can decide what the intervention is." (Ppt 5)*

As spoken to here, the PTMF as a viable service delivery model was further interpreted from participants emphasising the impracticalities and exclusivity of pathway structures within services, *"sometimes we lose people because everybody's got entirely different circumstances, if somebody's on a dementia pathway and a behaviour that challenges pathway and a mental health pathway, you know, really, we should just be saying what do they need?!" (Ppt 4).* Thus, suggesting that a PTMF-informed service model could overcome this by allowing for flexible, needs-led, and trauma-informed support for people with learning disabilities.

Theme 4: "There's still a way to go" for PTMF in Learning Disability Contexts (and beyond)

The final theme reflects that despite the perceived conceptual and practical utility of the PTMF, there are barriers to implementing the framework. The challenges highlighted by participants often pointed to the PTMF being at odds with how services operate and the current climate of services, "*understandably, how much energy do people have to engage with that [PTMF] given the context that we're in with regards to the level of strain that are on services" (Ppt 3)*. This theme encompassed two subthemes: (4.1) PTMF is at odds with current NHS service systems and (4.2) navigating challenges and controversy sharing PTMF ideas. Nevertheless, most participants spoke of the impediments as an important challenge to lean into for optimising person-centred care, as one participant summarised:

> "*I think the pressure to 'do' it right in the system at the moment is very powerful, but actually, the PTMF is about working with the person to 'get' it right … It's a really, really important challenge, because doing it right will not help, doing it right is not helping people." (Ppt 8)*

4.1 PTMF is at odds with current NHS service systems

There was a general sense shared among participants that the PTMF does not fit with current service structures and ways of working. Participants expressed that the conceptual fit of the PTMF for people with learning disabilities as outlined in theme one is at odds with the dominant medical model that often governs services, such as the NHS:

> *"I think there's still a way to go, and I think ideologically in the way that services are set up, it's still very psychiatrically dominated and kind of medical model heavy." (Ppt 3)*

Some participants explained that they feel the medical model, and professionals practicing in those ways, are *"really very powerful at the moment" (Ppt 8)* which ultimately impedes different ways of working, such as the PTMF, being easily implemented:

> *"I can think of loads of ways [PTMF] could be used as a whole service, but they won't be … they won't be because the people who hold the power at this point in time are invested in a medicalised view of people. Well, a reductionist view of people, not a trying to make sense of." (Ppt 2)*

Additionally, participants reflected on a specific lack of fit between the PTMF and traditional methods for acquiring outcome data and empirical evidence. Participants highlighted the intricacies around measuring outcomes when working with people with learning disabilities and their systems, especially when using flexible approaches to psychological formulation, such as the PTMF:

> *"Because loads of this [PTMF] stuff is nuanced, we're talking about working with humans, aren't we? And they're not, it's not scientifically measured, is it? And it can't be. It'll be those implicit changes that make a big difference and they're really hard to measure." (Ppt 1)*

> *"I think it's [PTMF] hard to evaluate because as soon as you get into saying what's happened to you … and you're looking at context…The ability to demonstrate a clear, marketable outcome in this society, diminishes, and people don't wanna buy that. And I think that's the biggest challenge is that we live in a world that wants to categorise, simplify, input output, commoditise, sell…sadly. But it would be great if there were some services that are set up like this and really thought about a different way of thinking about outcome." (Ppt 2)*

Thus, suggesting that evaluating the impact of the PTMF cannot and arguably should not be confined to fit with current methods, and instead systems ought to consider alternative ways to think about outcomes around the PTMF. However, participants described the pressure that prevails within services for quantifiable outcomes:

> *"Sometimes people go 'yeah, that's great, but what are we doing? We need outcomes, we need this, we need that.' So, we still are working in a system that needs some quite tangible evidence of things changing or being different." (Ppt 1)*

One participant highlighted that ultimately a big challenge of the PTMF for current systems is that "*at the moment, there is no evidence and that's the other issue I have with it" (Ppt 7).*

Taken together, participants ultimately reflected that it is challenging drawing on the PTMF in services underpinned by medical models, *"because doing this [PTMF] in a system that believes that [medical model], it's really hard" (Ppt 2)*. However, most participants advocated that, *"the PTMF is really timely, but it's an antidote to the dominant model at the moment, so that's really difficult for people to take in" (Ppt 8)* but nonetheless *"it's that chipping in and chipping away" (Ppt 1)*.

4.2 Navigating power when sharing PTMF ideas

Participants spoke of their experiences sharing PTMF ideas within learning disability systems, which appeared to pose challenges linked to the perceived lack of fit with current ideologies in services. It was inferred that some participants felt a sense of professional responsibility to address power within services by sharing PTMF ideas, though achieving this is challenging as current systems can feel very powerful. For example, some participants expressed feeling as though they are *"in a minority" (Ppt 2)* advocating for an alternative understanding of people with learning disabilities:

> *"It's very hard to stand up in an MDT for somebody … when they're wheeled in with 13 people to sit around the table and then the client comes in and you're talking about them and they're all saying what they've 'got'. It's very, very hard to be the person who puts their hand up and says, you know, this is my understanding from speaking to the person about how these experiences relate, and why you've seen what you've seen and why it makes sense?" (Ppt 2)*

Moreover, some participants reflected on their experiences of holding this alternative perspective and how they navigate this within systems:

> *“I'm really mindful about how I guess the ideas would be received by, like psychiatric colleagues and how do you want to position yourself at work, you know? How easy or difficult do you want to make your life at work as well? Or how much support or how many allies would you have for some of these ideas or ways of working?” (Ppt 3)*

Thus, some participants highlighted that the PTMF could disrupt professional relationships and were cautious about how they shared PTMF ideas within systems. Related to this, these challenges and some participants’ apprehensions around disrupting systems appeared to relate to navigating the controversy surrounding the PTMF. Most participants acknowledged the broader divisive debates regarding the PTMF, mainly thought to be caused by the nature of the ideas being at odds with those dominating services and beyond:

> *“I think underlying a lot of this is an interdisciplinary rivalry and different ideological power and different ideas about how people understand human distress.” (Ppt 3)*

> *“I think that the PTMF has been kind of created by quite loud voices and has been received quite critically as well hasn’t it, by those who may not agree with it fully.” (Ppt 1)*

In addition, one participant reflected that the PTMF has been controversial in learning disability contexts due to being interpreted by some as suggesting IDD diagnoses should be abandoned, which they highlighted would not fit:

> *“But if you imagine you ended up with a twenty-year-old man with Prader Willi syndrome who had a mild learning disability, and we were to abandon diagnostic labels. Good luck! You know, designing a formulation that addresses that man's treatment and needs, without recognising that he has Prader Willi syndrome, and I'm not sure the authors would do that or are saying that actually, in the way that I'm articulating it. But you know, there is this kind of push to, let's abandon, and that's how it's been interpreted by, I guess, the public… let's get rid of diagnosis, let’s just get rid of diagnosis and just work within the PTMF. And you kind of think, well, what?! That's not gonna work for LD, it's just not gonna work.” (Ppt 7)*

However, another participant suggested that aside from the diagnostic debates, the PTMF could more harmoniously *"filter through into the makeup and the nuts and bolts" (Ppt 1)* of learning disability services, rather than "*come in all guns blazing like it did maybe in some arenas … [because] it certainly should be thought about" (Ppt 1).* Ultimately, though implementing the PTMF can be challenging due to navigating powerful dominant ideologies, most participants saw this as a necessary advocacy movement:

> *"I think another sort of benefit of [PTMF] is that it's a statement made by people within the BPS, which OK might not represent everybody in the BPS's point of view, but it actually is clinical psychologists taking a stand on something … And I think that's really important for young psychologist coming through to see that this is something that we can do. So, there's a sort of content level and there's a process level of, you know, we're no longer a professional ally to medicine, well, certainly not pseudo-medicine, and we should be questioning these things as scientists and as people interested in the stories people tell, and the meanings in people's lives … I think otherwise, we're sort of, power without responsibility ourselves … if we don't do it, then we're culpable, aren't we? We're complicit with those understandings and problems that we see within that, unless we don't of course, but I think if we're not going to do this, then, who else is?" (Ppt 2)*

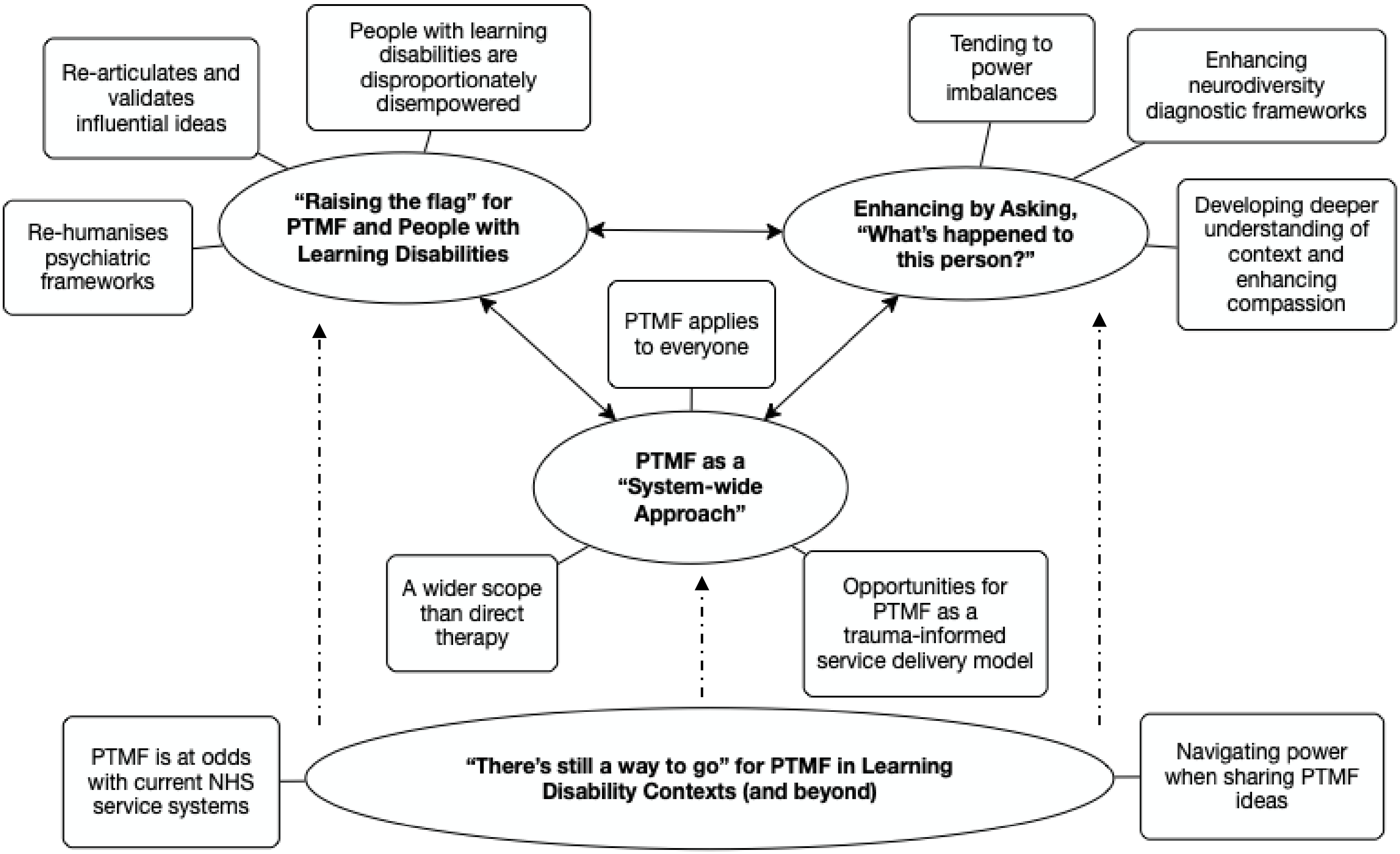
Overall Story of the Data

An overall analytic story of the shared patterns among views and experiences of participants was interpreted to tie together the four themes. It is proposed that the PTMF has a valuable contribution to offer working with people with learning disabilities and their systems. Most participants celebrated the paradigm shift away from psychiatric diagnoses offered by the PTMF, and the usefulness of considering what has happened to a person when working supportively with individuals and their support networks. The felt sense and explicit expression of enthusiasm for this humanistic, non-pathologising, and compassionate position was immense throughout the interviews. Ultimately, participants appeared to be advocating that people's (societies, organisations, professionals, and families) understanding of people with learning disabilities need to be supportively questioned and positively reformed, and the PTMF may help facilitate this if only there was a way for it to be introduced within services harmoniously. That is, the PTMF is not perceived as inherently positive by all and thus there is some way to go in either adjusting the application of the framework to fit with current service philosophies or adjusting current services to fit with the PTMF philosophies.

A thematic map (Figure 1) was created to illustrate the interpreted thematic story and relationships between themes and subthemes. The four themes and related subthemes were mapped to represent their relatedness, with the arrows indicating potential connections and influences between themes, rather than causality.

Figure 1

Thematic Map



Firstly, the bi-directional relationship between ‘Raising the flag’ and ‘Enhancing by asking’ refers to how the conceptual relevance of the PTMF appeared to inform its use and conversely the practical application reinforces the conceptual underpinnings. Next, the two-way relationship between ‘Raising the flag’ and ‘System-wide approach’ demonstrates how to widely advocate for PTMF ideas they must be shared at a system-wide level and implementing the PTMF as a system-wide approach further raises the flag for these ideas. Then, the bi-directional link between ‘Enhancing by asking’ and ‘System-wide approach’ demonstrates the system-wide applicability of considering how power is operating amongst everyone at all levels. Finally, the relationship between ‘There’s still a way to go’ and the other three themes refers to the impeding influence of the challenges on fulfilling the proposed applicability of the PTMF. That is, there appears to be a prerequisite to fit with or re-shape learning disability services before the PTMF can be implemented meaningfully.

Discussion

This is the first known study to explore the power threat meaning framework in the context of people with learning disabilities and their systems. This research aimed to provide novel insight into the applicability of the PTMF in adult learning disability contexts, through a qualitative exploration of professionals’ experiences and perspectives, including the perceived opportunities and challenges of utilising the PTMF for this population. A further aim was to address gaps in knowledge around PTMF and people with learning disabilities to inform implications for clinical practice and research. Thus, the findings will be discussed in relation to existing literature, the strengths and limitations of the current study, and resultant clinical implications and directions for future research.

Four themes and 11 subthemes were interpreted through reflexive thematic analysis relating to psychological professionals’ perspectives on and experiences of drawing on the PTMF in their work with adults with learning disabilities and their systems. Thus, it is important to explicitly state that findings convey the opinions of eight psychological professionals only. There was a strong consensus among participants that the PTMF is conceptually applicable to the lives of people with learning disabilities. This was linked to the framework's conceptual focus on negative operations of power in peoples' lives, leading to the perception that the PTMF is perhaps particularly relevant in learning disability contexts where individuals experience disproportionate disempowerment (Whaley et al., 2018). In particular, participants highlighted relational power and adverse interpersonal experiences as pertinent in the lives of people with learning disabilities, which is similarly emphasised by recent literature (Davies et al., 2021; Hammarlund et al., 2022). Moreover, it was proposed that the PTMF makes the links between psychosocial adversities, such as interpersonal trauma, and increased prevalence of psychological distress among people with learning disabilities (Sheehan et al., 2015) more explicit. Thus, it is possible that the PTMF may offer a conceptual framework that can capture the complex aetiology of distress in this population, which is often recognised inconsistently and arguably misunderstood or over-shadowed using psychiatric classifications and separate considerations of behaviour (Mason & Scior, 2004; C. Oliver et al., 2022). However, the PTMF could benefit from further exploration of theoretical underpinnings in relation to the lives of people with learning disabilities to further develop and validate these findings.

Theme 1: "Raising the flag" for PTMF and People with Learning Disabilities

Captured by the theme name 'raising the flag', it was found to be important to psychological professionals to represent PTMF concepts within learning disability contexts, which were identified to re-articulate and validate existing influential ideas such as the social model of disability (Gillman et al., 2000). This finding is supported by Fyson et al. (2019), who posited that the PTMF provides a unifying framework to encompass the comprehensive theoretical bases for social components of distress. Also, current findings suggest the PTMF validates working in line with these philosophies by providing a framework to apply in practice to ensure these ideas are not forgotten. Thus, it is proposed that the PTMF goes beyond implicit understandings of power within such existing social models by providing a conceptual framework that can be clinically applied to explicitly outline, question and influence power imbalances. Likewise, having such a framework was valued to re-humanise the understanding of psychological distress of people with learning disabilities posed by psychiatric models. That is, participants spontaneously reflected on the arguable and well documented (J. Morris, 2001) human rights issues associated with biomedical models of distress, such as the prevailing over-medication of people with learning disabilities (Branford et al., 2018b), and positioned the PTMF as a humanising alternative. This proposed strength of the PTMF is of heightened importance for people with learning disabilities due to over-medicalisation (Goble, 1998; Hudson, 1991) and persisting dominance of the biomedical model in the care of this population (Deb et al., 2022), which was also noted by participants. Thus, findings infer that in using the PTMF, psychological professionals are seeking a humanising conceptual framework to better understand the lives of people with learning disabilities than does the biomedical model, supporting the aims of transforming care (DoH, 2012). Taken together, these findings suggest that the PTMF aligns with the values of these learning disability psychologists, and perhaps the aspirations of learning disability services.

Theme 2: Enhancing by Asking, "What's Happened to this Person?"

A sense of practical applicability of the PTMF to learning disability contexts was interpreted from participants' accounts, which repeatedly described enhancements to existing ways of working. Findings suggest that the PTMF is being applied integratively and thus participants were not often explicitly using the framework in its entirety, rather frequently posing PTMF core questions in their work, such as 'how is power operating in this person's life?'. There was a focus on the usefulness of the PTMF as a tool to explicitly tend to power imbalances in indirect working contexts, such as MDT team formulations and consultations with care staff, to exemplify the importance of empowerment and autonomy for people with learning disabilities (Lysaght et al., 2009). A similar emphasis on utilising the PTMF to facilitate reflections on power has been reported by clinical psychologists in adult mental health contexts (Travers, 2022). In addition, current findings propose that the power part of the PTMF offers a novel and distinct contribution to dominant learning disability frameworks, such as PBS. That is, the PTMF was perceived to facilitate valuable and unique considerations of power in the formulation of behaviours that challenge by linking power imbalances to behaviours, or people's threat responses. Thus, this study found that professionals are integrating the PTMF within PBS approaches to provide a richer understanding of individuals, as it was acknowledged by participants that PBS lacks such contextual considerations which may lead to ineffective support, as recognised by research (Hassiotis et al., 2018). However, despite perceived enhancement, it is unclear from the findings of this study to what extent tending to power in these ways improved outcomes for the individuals supported. Still, the operation of power is a central part of the PTMF and represents much of the theoretical evidence-base linking social context to distressing experiences (Boyle, 2022), which is arguably essential to consider in psychological models in learning disability settings and within broader ways of working.

Similarly, exploring the PTMF core question 'what has happened to this person?' with an individual's support network was perceived to develop a deeper understanding of their historic and current context compared to existing models. Thus, findings suggest that the PTMF is being used as a tool to emphasise a person's context and encourage others to consider displays of emotional and behavioural distress in relation to what's happened to them. Participants spoke to the significance of exploring a person's life experiences within team formulations, which are often not known by staff (Costello et al., 2007), and observing 'light bulb' moments of staff understanding their clients better and positive shifts in support. However, such findings are based on anecdotal observations, though quantitative studies have demonstrated similar deeper understanding resulting from psychological formulation in mental health teams (Berry et al., 2009; Summers, 2006). Yet findings are inconsistent (Wilkinson et al., 2017), and thus as reflected by participants, it is important to reflect on the power professionals hold and the dilemmas of sharing client information in such formats due to potential harm for individuals, such as violating trust (Hartley, 2021). Thus, as recommended by other studies (Lewis-Morton et al., 2017), findings suggest a PTMF formulation should be co-produced with clients as not to perpetuate or exacerbate disempowerment, the very thing that the framework hopes to address. This finding overlaps with recent PTMF guidance for learning disability contexts, where many individuals would not be able to co-produce their formulation, and thus a PTMF narrative cannot be developed for a person but instead the framework core questions can be used to inform thinking around a person (G. Collins et al., 2022b).

Relatedly, findings of the current study propose that using the PTMF core questions indirectly to guide others' thinking around a person has the potential to enhance empathy and compassion amongst people's support networks. That is, the understanding offered by the PTMF was described as normalising and non-blaming, allowing staff members to put themselves into the shoes of individuals they support. It is possible that the narrative style of the PTMF core questions centres a person's life story, perhaps allowing shifts from problem-saturated and unempathetic perspectives to compassionate and empowering alternatives. This link between storytelling, empathy and healthcare practice is well researched (Frank, 2016). Inviting people to think about what another person might experience, and how they may think and feel, as does the PTMF, has been found to foster emotional connections between people and resultant empathy (Fairbairn, 2002; Manney, 2008). This is arguably especially important for this population, who are often highly stigmatised (Scior et al., 2020) and viewed negatively even by professionals (Ee et al., 2022). Moreover, a lack of contextual information and thus empathy around clients has been found to result in negative attitudes among staff and abusive and restrictive practices towards clients (Hutchinson et al., 2014). Addressing this compassion fatigue in staff has therefore been posited as key in preventing further abuse of individuals in health and social care settings (Richards, 2020). Taken together with the current findings, the PTMF could show promise in reducing and preventing abusive practices towards people with learning disabilities by enhancing understanding and compassion among staff, both fundamental components of person-centred care (Brown et al., 2020). Though, it is unclear to what extent the PTMF enhances compassion beyond other models, and how this is experienced by staff and the individuals they support.

Linked with this, this study found the PTMF may enhance the understanding of neurodiverse individuals' experiences, such as autistic people who have learning disabilities, and is being positioned alongside neurodiversity diagnoses to add idiosyncratic understandings. This is relevant to learning disability contexts as participants acknowledged a large proportion of individuals are diagnosed with a neurodevelopmental condition (Matson & Shoemaker, 2009). The both-and approach adopted by participants has been documented by professionals drawing on the PTMF in autism services (Flynn & Polak, 2019), though there is no other research or guidance on the conceptual or practical applicability of the PTMF for neurodiverse populations. This may explain why participants were particularly mindful of drawing on the PTMF with people who identify or are identified as neurodiverse, as not to invalidate such diagnoses, whilst hoping to ensure a person's individual context is considered. Thus, participants appeared to use the PTMF alongside neurodiversity diagnoses to embody that people should be given choice in how they understand their experiences (Cooke & Kinderman, 2018), whilst appreciating the importance of neurodiversity diagnoses for some people, such as to access specialist services (Cluley et al., 2022). This fits with guidance from the PTMF authors regarding diagnoses generally, that the framework is one available option rather than an absolute alternative, as it has been interpreted by some (Johnstone et al., 2019). Findings from this study suggest that professionals are seeking further guidance to inform their practice in this area, particularly from the perspective of people with learning disabilities who identify as neurodiverse.

Theme 3: PTMF as a "System-wide Approach"

In line with the applicability of the PTMF to indirect work predominantly, the current research study findings suggest that the PTMF has a wider scope than direct therapy and is best applied systemically to influence systems around people with learning disabilities. This finding aligns with the notion that a systemic approach is particularly fitting for individuals as they are likely to have large support networks (Baum, 2006; Kaur et al., 2009), and thus is becoming increasingly encouraged (Baum & Lynggaard, 2018; Haydon-Laurelut et al., 2009). Moreover, adults with learning disabilities have identified that working effectively with their support network is a key attribute of professionals (Weise et al., 2018). In particular, findings highlighted that the PTMF can be used to acknowledge multiple positions within a client's system, which is helpful given the inherent relational nature of care and support for this population (Haydon-Laurelut, 2009). That is, the PTMF can relate to operations of power, meanings, and threat responses in everyone's lives, including professionals, care staffs, and families' experiences and consider how these may interact with clients' experiences. This is relevant given the challenges posed to people supporting individuals with learning disabilities in distress and suggests the PTMF may be helpful as an indirect tool to supportively understand such experiences, as described with carers elsewhere (Paradiso & Quinlan, 2021). Ultimately, the PTMF is predominantly being applied systemically in learning disability contexts and could help to further emphasise the importance of how individuals live their lives relationally and provide support that acknowledges this (A. Power et al., 2022).

Of note, this study found that only a couple of professionals were drawing on the PTMF within direct therapy with people with mild learning disabilities. Generally, there were reservations around the utility of the PTMF for therapy in this context due to an array of factors, including a lack of empirical evidence, resources, and guidance for doing so, as well as perceiving it inappropriate to try and address systemic injustices of power in direct therapy. Though, as some participants were beginning to draw on the PTMF directly and with perceived positive impact, it will be important to continue to gain feedback and practice-based evidence on the PTMF narrative from the perspectives of individuals themselves. This fits with the progressive self-advocacy movement and research promoting life storying for all people with learning disabilities (Ledger et al., 2022).

Reflecting on the systemic applicability of the PTMF throughout the interviews, participants identified opportunities for the framework to be applied as a whole systems approach to promote trauma-informed service delivery. That is, the PTMF was proposed as a timely framework that could support the culture shift towards TIC within learning disability services. For example, participants offered ideas around using the PTMF as an initial assessment tool to better understand a person's history, current experiences, and resultant support needs to inform their care. These findings support anecdotal propositions that the PTMF can be used to adapt mental health services and facilitate TIC to ensure people are being helped in more trauma-informed ways (Bostock & Armstrong, 2019; Mitchell & Thorne, 2019). It is possible that this has specific utility for learning disability services as a screening process to identify trauma, considering the challenges that remain in the recognition and assessment of trauma in this population (McNally et al., 2021). Moreover, the current findings extend established links between the PTMF and TIC by suggesting that the framework can be applied to everyone in a system to understand and support people at all levels, including professionals and care staff. Ultimately, the potential for the PTMF to be applied at a system-wide level could support transforming care initiatives and related policy-level change in how we think about psychological distress and distressed behaviour in people with learning disabilities by elucidating links to systemic power (Read & Harper, 2022; Whaley et al., 2018).

Theme 4: "There's still a way to go" for PTMF in Learning Disability Contexts (and beyond)

Importantly, undermining the perceived conceptual and practical applicability of the PTMF in learning disability contexts were an array of challenges implementing the framework identified by participants based on their experiences. Key barriers to applying the PTMF related to a perceived lack of fit between the framework and biomedical approaches, which govern NHS mental health services (Barnes et al., 2022), including learning disability services (Williams & Heslop, 2005). Similar challenges negotiating the implementation of the PTMF within traditional services have been reported elsewhere (Travers, 2022). Of note, one participant reflected that the PTMF could be interpreted as suggesting we abandon diagnoses and biological factors, which was perceived to be at odds with learning disability contexts where individuals commonly experience genetic conditions. Though of note, the PTMF guidance openly endorses such factors as key contextual considerations (Boyle & Johnstone, 2020; Johnstone et al., 2019), which suggests this has been overlooked or misunderstood by some parties. Thus, the PTMF could be positioned as an enhancement rather than a replacement of these conditions. This may be an area for future enquiry as diagnostic classifications for people with learning disabilities and co-occurring neurodevelopmental conditions continues to evolve alongside the preferences of individuals (Thurm & Srivastava, 2022).

A specific perceived barrier to systems embracing the PTMF were complexities in measuring outcomes and services striving for routine outcome measurements and evidence-based practice. It is undoubtedly important to ensure people are receiving the safest and most effective care, yet practice-based evidence has long been deemed appropriate and meaningful for people with learning disabilities (Gates & Atherton, 2001; Man & Kangas, 2020). More specifically, person-centred care is an individualised entity rather than a standardised approach to care and can be hard to objectively measure (A. Power et al., 2022). Participants compared drawing on the PTMF to such individualised approaches and reflected on the challenge of measuring complex systemic processes that may result from using the PTMF. Findings suggest that empirical research of various applications of the PTMF in learning disability settings would need to utilise more subjective measures, such as goal setting and individualised outcome measures (Young & Chesson, 2006), which align with best practice research (J. E. Taylor & Taylor, 2013). However, one participant advocated for rigorous traditional randomised trials to investigate the efficacy of the PTMF. Similar critique has been noted elsewhere, suggesting the PTMF problematically defies empirical research-led progress in mental health (Salkovskis & Sutcliffe, 2018). However, reducing such individualised approaches into streamline and measurable outputs disregards the values and purpose of person-centred care (Denne et al., 2020). Thus, the findings of the current study indicate that further work into how the PTMF can be meaningfully and reliably measured, especially in learning disability contexts, is required.

Ultimately, the current study suggests there is still a way to go before the PTMF could be fully and meaningfully implemented within learning disability settings. That is, findings suggest that it is challenging for professionals to work from a position of ‘what has happened to this person?’ in systems that seek to know ‘what is wrong with this person?’. This relates to previous studies exploring challenges working beyond the biomedical model in adult mental health services (Cooke et al., 2019; Randall-James & Coles, 2018). As described by Cooke et al.'s (2019) model for navigating biomedical systems as a psychologist, participants in the current study appeared to navigate using ‘compromise’ or ‘conflict’. That is, most participants appeared to strategically draw on the PTMF where possible, whereas a few positioned themselves as drawing on the PTMF to advocate against the dominance of psychiatric diagnoses (Randall et al., 2022). Building on Cooke et al.'s (2019) proposed strategies for managing such challenges, it is possible that the PTMF itself could represent a strategy. As discussed by Fyson et al. (2019), the PTMF has potential to facilitate and strengthen multi-disciplinary working with psychiatry colleagues by providing a framework grounded in evidence to defend the need to consider a social perspective of distress, and thus empower non-psychiatrists to actively contribute to MDT discussions. Though, it appears professionals in the current study mainly used the PTMF to gently chip away during conversations with colleagues as described elsewhere (Christofides et al., 2012). Nevertheless, participants expressed that despite challenges, and in line with the desire to *"raise the flag"*, enthusiasm prevails to advocate for this different way of working and to be part of psychologists *"taking a stand on something"*. In this context, the re-humanisation and empowerment of people with learning disabilities.

Strengths and Limitations

This study used a clear and rigorous methodology to analyse the detailed accounts of eight psychological professionals. Demographic data suggests the participants had a wealth of experience working with people with learning disabilities and their systems and had been drawing on the PTMF for a considerable amount of time. Though it is important to acknowledge that participants were a self-selected sample with potential bias for positive attitudes and experiences regarding the PTMF. However, the interview schedule explicitly enquired around challenges related to the PTMF in hopes to invite and capture nuance. Indeed, there was variation in opinions among participants, with the researcher aiming to embrace negative perspectives by including minority viewpoints within the analysis to embody the nuance. Moreover, participant reflections were sought to provide reflective elaboration on the results, which appeared to closely resonate with their views and was reflected to provide a balanced account of differing opinions. Notably, though the study was open to professionals from any discipline, only psychological professionals showed interest in participating. This likely reflects the workforce who are aware of the PTMF and are drawing on it, though it will be important to seek opinions of other professionals, especially given the identified challenges sharing PTMF ideas.

A critical realist position and Big Q research values have been upheld throughout this study. Therefore, this research represents the researcher's subjective interpretation of a particular group of professionals' experiences based on their unique accounts and perspectives at one time. Thus, this study did not aim to objectively measure or assess the application of the PTMF, but rather provide a trustworthy interpreted understanding of potential applicability through engaging with the research process rigorously and transparently. This was upheld by following various guidance for high quality qualitative research (Braun & Clarke, 2021b; R. Elliott et al., 1999). Moreover, qualitative methodology facilitated a rich breadth and depth of insight into experiences and perspectives surrounding the PTMF to come forth that would not have been possible with quantitative methods. The epistemological position underpinning this study meant that it did not seek to achieve or provide generalisability in the positivist sense (Smith, 2018). However, analytic generalisability (Firestone, 1993) was achieved in the study through providing novel conceptual insights and interpreting these in the context of relevant literature. In addition, contextual information was provided to allow for transferability (Polit & Beck, 2010), meaning that readers can make judgements regarding the applicability to their contexts. It is hoped the findings are relatable and have meaningful utility to other professionals working in learning disability contexts and beyond.

Finally, and perhaps of most significance, this study regrettably lacks the perspective of people with learning disabilities and their direct support networks. Though, this study was considered a necessary first step in exploring the implementation of the PTMF in learning disability contexts. Given that it is now evident the framework is being utilised in this setting, it is vital to seek perspectives of the people the implementation of the PTMF involves and impacts.

Implications for Practice

This study elucidated the applicability of the PTMF in the work of psychological professionals with people with learning disabilities and established potential clinical utility to provide a humanistic way of thinking about and working to support this population. Thus, professionals seeking a framework that recognises and addresses the disempowerment in the lives of people with learning disabilities, fits with social models of disability and validates working in this way, and offers a more humanising understanding of distress than psychiatric models, would likely be interested in the PTMF. Interested readers are directed to the recent PTMF guide for learning disability contexts (G. Collins et al., 2022b). Moreover, the PTMF could be used as a conceptual framework to inform policy and related training and education of health and social care professionals and care staff regarding the experiences of people with learning disabilities and psychological distress. This fits with endeavours to ensure policies account for factors that maintain and increase inequality and discrimination of this population (Houck & Dracobly, 2023a) and the National Institute for Health and Care Excellence quality standards regarding the prevention of distress among people with learning disabilities (NICE, 2016).

The findings of this study propose the PTMF may be a useful tool to highlight and address power imbalances in various aspects of clinical practice. This has specific implications for learning disability settings, for example to enhance the assessment, formulation, and intervention for people who are distressed and displaying behaviours that challenge and to highlight, reflect on, and reduce restrictive practices in inpatient settings. Similarly, the PTMF's focus on what has happened to a person could be used to enhance contextualised understandings of people's distress, for example in complex care conferences, to ensure ensuing care plans meaningfully reflect the persons experiences and needs. Participants in this study posited that the PTMF may foster compassion among people's support networks, which could be particularly relevant in such complex situations where a systems empathy may be challenged, and risks of coercive and abusive practices heighten. At a basic level, the PTMF could help to ensure all people with a learning disability are provided with sufficient, personalised support to ensure they lead empowered lives, by ultimately advocating to reduce and prevent negative operations of power.

Linked with this, the PTMF could assist in the assessment of people with learning disabilities' care needs and prevent common diagnostic overshadowing in this population (Longfellow & Hicks, 2022), for example by considering behaviours that challenge as related to trauma and psychosocial adversity rather than disability (Rittmannsberger et al., 2020). This links to TIC initiatives to identify and support trauma survivors and prevent re-traumatisation, thus the PTMF could be used to support the implementation of TIC. For example, clients could be invited to co-produce their PTMF narrative formulation when they first meet with services, which would help to screen for psychosocial adversity and its impact, to guide decisions about the best approach to care. Though this would likely require the development of easy-read or more user-friendly versions of the PTMF and would not be possible for all individuals. However, this model could address challenges in recognising and assessing of trauma in people with learning disabilities (McNally et al., 2021), which is often missed due to not being able to communicate and misunderstanding distress in this population (Daveney et al., 2019). That is, by explicitly emphasising power and linking this to psychosocial adversity and different expressions of psychological distress, the PTMF would ensure that historic and current adversities are explored directly or indirectly with people's support networks. Explicit consideration of power could work to shift the balance of power and improve delivery of transforming care initiatives (Whaley et al., 2018). Moreover, alike TIC, PTMF ideas were acknowledged to be widely applicable and thus could be useful in understanding and supporting the needs of care staff and professionals. This may have implications for promoting staff wellbeing and retention, which is a huge challenge in current UK learning disability contexts (Buchan et al., 2019; Ryan et al., 2021).

Given challenges implementing the PTMF, for professionals who are interested in drawing on the framework it will likely be important to collaborate with other professionals, ideally across disciplines for training and supervision opportunities. Many people with learning disabilities are also served within general mental health services (Pinals et al., 2022b), so these findings may have relevance for psychologists and professionals in other settings. In addition, there are implications to consider for engaging in macro level public health campaigns, which fits with progressive community psychology and social change approaches (Richards, 2022). Linked to this, findings suggest that the PTMF shows promise as a de-stigmatising framework of mental health, which has been shown elsewhere to improve lay people's attitudes and decrease desire for social distance of people who experience psychosis (Seery et al., 2021). Thus, one idea to widely implement the PTMF in social policy relates to perhaps using virtual methods to share people's stories using the framework, as being demonstrated in other marginalised populations (Sljivic et al., 2022).

Directions for Future Research

To build upon the findings of this study, which focused on psychological professionals' views and experiences, it will be important for future research to explore how the PTMF concepts fit from the perspectives of other professionals, care staff, and people with learning disabilities and their families. For example, to investigate whether social workers are drawing on the PTMF in learning disability settings and to gather their perspectives, as the framework has been identified as a useful resource for social workers (Fyson et al., 2019) who also commonly work closely with people with learning disabilities to advocate for personalised care (Sims & Cabrita Gulyurtlu, 2014). In addition, further exploration from the perspectives of people with learning disabilities, including possible uses of PTMF within direct therapeutic support, is required. This would likely require the development and evaluation of adapted materials with which the PTMF could be more easily accessible to individuals with varying cognitive abilities (Johnstone et al., 2019). Thus, a beneficial next step to further inform the implementation of the framework may be to empirically explore feedback from multiple perspectives (people with learning disabilities, their families, care staff, and MDT professionals) of the recent PTMF guide created for learning disability contexts (G. Collins et al., 2022b).

Linked with this, as the PTMF is being applied systemically by psychological professionals, it is important to find ways to measure the impact and outcomes from this implementation. For example, researchers could investigate whether team formulations that integrate the PTMF lead to different outcomes compared with other models, such as the ‘5 Ps’ model. Similarly, given the finding that professionals are using the PTMF integratively to enhance their practice of PBS, it would be interesting to implement and evaluate behavioural-focused interventions informed by a PTMF formulation for clients and their systems, and compare this to conventional PBS interventions. Lastly, findings proposed that the PTMF could, and arguably should, be applied as a system-wide approach and may support the implementation of TIC. To explore this further, pilot studies could trial such a service delivery model and assess the system-wide outcomes for professionals, related agencies, and importantly people with learning disabilities.

The findings of this study highlighted a gap in conceptual knowledge and practical guidance regarding the PTMF and neurodiverse populations which requires further exploration. Moreover, this study did not relate to children and young people with learning disabilities and their families, which could be a next step in research to determine how the findings of this study fit or differ. Ultimately, whether researching the PTMF at direct, indirect, or system-wide level, it is key to endeavour to include people with learning disabilities and their direct support networks in the development and execution of research in meaningful ways (Burack et al., 2021; Mactavish et al., 2000).

Conclusion

Given the disempowerment faced by people with learning disabilities, it is arguably crucial that conceptual frameworks consider power and advocate for empowerment in understanding, supporting, and preventing psychological distress in this population. The PTMF likely offers such a framework, though was developed in adult mental health contexts and has not yet been researched in learning disability settings. Thus, the current study provided novel insight into the applicability of the PTMF for people with learning disabilities from the perspectives of psychological professionals. The findings suggest a perceived conceptual applicability and particular relevance of the PTMF for people with learning disabilities, embodied by enthusiasm amongst professionals to ‘raise the flag’ for the PTMF in learning disability services. The PTMF appears to be most practically applicable to indirect work, where professionals are using the framework integratively to enhance understanding of and compassion for people's experiences within existing models such as PBS. Moreover, the PTMF was considered a whole systems approach, with professionals advocating for the implementation of the framework more broadly within services as a trauma-informed approach, in line with TIC. However, challenges were highlighted regarding a lack of fit with current services, including dominance of the biomedical model and related complexities demonstrating positive outcomes. Thus, there remains a way to go for the PTMF in learning disability settings as professionals begin to navigate advocating for such philosophies. Future research is required to explore the perspectives of people with learning disabilities and their direct support networks in relation to the PTMF and to meaningfully explore the impact of using the PTMF in these contexts. Though ultimately, the PTMF shows promise in the longstanding pursuit to address the disempowerment of people with learning disabilities and foster empowering circumstances in which individuals can thrive.

Key messages and implications:

1. This is the first known study to explore the applicability of the PTMF in the context of working with people with learning disabilities and their support networks. Findings indicated that professionals perceived the PTMF as conceptually applicable and particularly relevant to the experiences of people with learning disabilities.
2. Psychological professionals are beginning to draw on the PTMF systemically to enhance thinking around and support for individuals with learning disabilities by asking, ‘how is power operating in this person’s life?’. Thus, the PTMF could be used as a tool to highlight and address power imbalances and may foster compassion within clinical practice.
3. Opportunities were identified for the PTMF to be adopted as a trauma-informed whole systems approach. Though challenges were identified navigating current service structures and evaluating outcomes of PTMF-informed service delivery.
4. Further research is required to explore the applicability of the PTMF from the perspectives of people with learning disabilities, their support networks, and other professionals, as well as to empirically explore outcomes from implementing the PTMF in clinical practice.

Paper 2: What is Known About the Application of Trauma-informed Care Within Services for People with Intellectual and/or Developmental Disabilities?

Abstract

Trauma-informed care (TIC) is gaining momentum in various health, social, and educational settings globally in response to the widespread pervasiveness of adverse experiences and resultant psychological trauma. Given that people with intellectual and/or developmental disabilities (IDD) are more likely to experience traumatic life events than the general population, it makes sense that TIC should be in place within services supporting individuals with IDD. Yet there is a dearth of empirical research exploring the integration of TIC in such organisations and the spread of limited available literature is diverse. Thus, this paper aimed to scope and synthesise the emerging literature to elucidate what is known regarding TIC in the context of IDD. A scoping review was conducted using the Arksey & O'Malley (2005) guidelines. Three databases, PsycINFO, Web of Science, and PubMed, were searched using relevant search terms to retrieve 69 papers published since 2000, which were systematically screened for eligibility. Twenty-three papers comprising a range of source types met inclusion criteria and were reviewed rigorously, with included empirical studies appraised using the mixed methods appraisal tool (MMAT; Hong et al., 2018). The PAGER framework (Bradbury-Jones et al., 2022) was followed to generate four patterns from the findings: (1) Opportunities for Embedding TIC within IDD Contexts, (2) Incorporating TIC Principles into Specific IDD Service Models, (3) Implementing TIC across Micro, Meso, and Macro Levels, and (4) Challenges and Barriers to Implementing TIC in IDD Organisations. There is a growing body of literature exploring the implementation of TIC within IDD organisations, including newly emerging TIC training programmes for staff. Yet there remains a lack of empirical implementation research examining outcomes for service providers and recipients. Tentative evidence for clinical practice and research recommendations from each pattern of findings are discussed, along with strengths and limitations of this review.

Key words: intellectual and developmental disabilities, trauma-informed care, scoping review

Introduction

The last two decades have seen momentum build for the evolution of trauma-informed care (TIC) internationally (Harris & Fallot, 2001). This impetus to develop trauma-informed health and social care services is largely due to ever-growing recognition of the wide prevalence of early and persistent traumatic experiences and their impact on later psychological wellbeing and physical health amongst the general population (Oral et al., 2016; Racine et al., 2020). That is, most people in the general population have likely experienced trauma of some kind (Kilpatrick et al., 2013). Trauma-informed care is best described as a system-wide approach to address this pervasiveness of trauma, whereby organisations respond to all people, service recipients and providers alike, with practices based on principles of safety, trust, choice, collaboration, and empowerment (Harris & Fallot, 2001). Psychological trauma (hereafter referred to as 'trauma') is typically defined as a subjective experience that encompasses facing an overwhelming threat to a one's own or another person's physical or psychological safety, which compromises coping and resilience, and thus instigates enduring biological, psychological and social consequences (Boals, 2018; Christopher, 2004). In responding to this sequalae of trauma, services that adopt a trauma-informed approach are distinct from trauma-specific services, despite often termed interchangeably (DeCandia et al., 2014). Trauma-specific services offer targeted interventions to treat the symptoms of trauma (Berliner & Kolko, 2016). In contrast, trauma-informed services embody TIC principles within organisational culture and practices to be mindful of and respond sensitively to potential trauma-related issues, irrespective of the services provided or whether a person's trauma is known (Sweeney et al., 2016). Thus, TIC does not aim to address trauma sequelae directly, rather foster practices that minimise the likelihood of re-traumatisation and have potential to be indirectly healing (Butler et al., 2011; Purkey et al., 2018).

The early work of Harris and Fallot (2001) laid the groundwork for the TIC approach by postulating five core principles of safety, trustworthiness, choice, collaboration, and empowerment. To briefly describe each of the five tenets; (1) safety refers to providing a safe physical environment and interpersonal experiences, (2) trustworthiness is embodied by being sensitive, consistent, and reliable, (3) choice allows a person to advocate for their preferences and promotes (4) collaboration and a sharing of power to foster (5) empowerment, which enables people to realise their strengths and resiliencies. These principles are considered critical components for psychological healing and are core to human existence to promote emotional and physical wellbeing (D. E. Elliott et al., 2005). More recently, the substance abuse and mental health services administration (SAMHSA; 2014a) outlined four Rs of TIC, stipulating that trauma-informed approaches should work to realise trauma and its impact, recognise the signs of trauma, respond to trauma according to the five core principles, and actively resist re-traumatising people. Despite these influential models, there are misconceptions around what constitutes TIC and how to 'be' trauma-informed (Sweeney & Taggart, 2018). Though generally consensus posits that TIC represents a commitment to shifting organisational culture, policies, and practices to create a seamless trauma-informed environment that strives to prevent (re)traumatisation (Fallot & Harris, 2009).

The implications of disregarding TIC are vast, including inadvertent traumatisation and re-traumatisation of individuals and service providers, which can further perpetuate trauma sequalae and impede recovery (Sweeney et al., 2016, 2018). Furthermore, not only can a lack of trauma-informed practices be harmfully triggering, but also lead to inadequate understanding of individuals' presenting difficulties and thus a failure to intervene successfully or make appropriate trauma-specific referrals (Butler et al., 2011). The well-documented consequences faced by services in the absence of being trauma-informed have motivated a myriad of settings to begin implementing TIC (Reeves, 2015). Positive outcomes have been reported across services for looked after children (Bunting et al., 2019), residential settings for young people receiving psychiatric care (Bryson et al., 2017), in school-based programs (S. L. Martin et al., 2017), and within adult healthcare practice (Raja et al., 2015) and inpatient mental health services (Muskett, 2014), amongst others. For example, large reductions in restrictive practices and staff turnover, and significantly improved staff wellbeing and client satisfaction were demonstrated following TIC implementation in an addiction service

(Hales et al., 2019). However, little attention has been paid to TIC for marginalised groups, such as people with disabilities (Williamson & Qureshi, 2015).

A growing body of literature indicates that people with intellectual and/or developmental disabilities (IDD) are disproportionately affected by traumatic experiences (McNally et al., 2021; Wigham et al., 2011). Intellectual and/or developmental disabilities is an umbrella term for a variety of neurodevelopmental conditions people are diagnosed with, such as intellectual disabilities and autism spectrum conditions (ASC), which are usually present at birth and uniquely affect the trajectory of a person's physical, intellectual, and/or emotional development (Schalock et al., 2019). Using this broad term can be helpful in the context that many of these neurodevelopmental conditions co-occur (Salvador-Carulla et al., 2011), yet intellectual disability (ID) and developmental disabilities (DD) can be distinct, hence the 'and/or' used here (Schalock & Luckasson, 2021). Compared to other people, individuals with IDD are significantly more likely to experience adverse life events and abuse in childhood (Balogh et al., 2001; Lapshina & Stewart, 2021; Stewart et al., 2022), with this increased vulnerability to traumatic experiences persisting into adulthood (Newman et al., 2000; Wigham & Emerson, 2015). Importantly, these instances of childhood and adult trauma predict lower levels of psychological and physical health (Hughes et al., 2019). Such findings exposing the high prevalence of trauma among people with an IDD highlight the need for trauma-informed policies and practices in support services for this population (Cook & Hole, 2021). However, to date there is limited research exploring TIC within IDD services, despite the vast number of individuals who seek support through health and social care organisations (Pinals et al., 2022a).

The emerging body of research regarding trauma and individuals with IDD appears to be focused on exploring the identification of traumatic life events (Cook & Hole, 2021; Wigham et al., 2011) and trauma-specific interventions for post-traumatic stress disorder (PTSD; Keesler, 2020a; McNally et al., 2021; Mevissen et al., 2012, 2020; Mevissen & de Jongh, 2010). Whilst such studies go some way in addressing the widespread prevalence of trauma in this population by informing targeted support, there remains a large proportion of individuals who have been impacted by trauma but go unrecognised, unsupported, and perhaps even further traumatised by services (Kildahl et al., 2020). That is, due to various factors including communication difficulties, a person's experiences of trauma may be unknown, masked, or hidden (Wigham & Emerson, 2015). Likewise, the predominant focus on behavioural approaches within IDD services may not be suitable for such individuals whose behaviour is underpinned by misunderstood trauma responses (McNally et al., 2021). Together suggesting there is a significant risk of diagnostic overshadowing of trauma amongst individuals with IDD, where trauma sequalae is misinterpreted and attributed to the disability (Kildahl et al., 2019). However, TIC is not contingent on identifying trauma among individuals (Muskett, 2014) and thus offers an approach that addresses such pitfalls in trauma-specific assessment and treatment in this population (Keesler, 2014; McNally et al., 2021).

Moreover, a distinct philosophy of TIC is that the approach is applicable to and thus should be implemented at all levels, including amongst staff working in services (Harris & Fallot, 2001). This may be particularly relevant for IDD services, where care staff experience violence (Antonsson et al., 2008), secondary traumatic stress (Boamah & Barbee, 2022), and have also likely experienced trauma in their lives (Keesler, 2018). These factors have contributed to crises with staff burnout and retention, as well as negatively impacting on quality of care (Hewitt & Larson, 2007; Shead et al., 2016). Thus, trauma-informed organisational cultures may show promise to promote staff functioning and could be protective in preventing the (re)traumatisation of both individuals and care staff (Boamah et al., 2022).

Bearing in mind the array of factors pointing to the relevance of trauma-informed approaches for individuals with IDD and those that work to support them, it is arguably particularly important to implement TIC within IDD organisations (McNally et al., 2021). However, despite a call for the integration of TIC within IDD settings nearly a decade ago (Keesler, 2014), there has been a dearth of ensuing literature. Amongst the limited number of studies exploring the implementation of TIC in this context are studies within IDD day services (Keesler, 2016; Keesler & Isham, 2017), specialist health services (Truesdale et al., 2019) and community residential settings (McNally et al., 2022). Thus, a small number of papers are available on the topic, though there are no existing reviews that synthesise the available literature regarding TIC approaches within IDD settings.

Given the dearth and diversity of the existing literature and empirical research, a scoping review was chosen to map the available knowledge in regard to volume, nature and characteristics as there is lack of empirical research to conduct a systematic review to evaluate evidence (Pham et al., 2014). Scoping reviews are indicated when it is unclear what precise questions could be meaningfully addressed by a systematic review, thus are considered a precursor to a systematic review (Munn et al., 2018). Recently, a formal definition conceptualised scoping reviews as *"a type of evidence synthesis that aims to systematically identify and map the breadth of evidence available on a particular topic, field, concept, or issue, irrespective of source (i.e., primary research, reviews, non-empirical evidence) within or across particular contexts"* (Munn et al., 2022; p. 950). Thus, scoping reviews provide a methodology to synthesise emerging literature and facilitate initial steps in research development to inform practice, policy, and research (Peterson et al., 2017). Importantly, there is an abundance of available guidance advising researchers how to conduct robust scoping reviews (Pollock et al., 2021).

The aim of this review was to explore the status of existing literature regarding TIC approaches implemented within IDD organisations. A scoping review was conducted to systematically scope the literature in this area, establish clinical implications and identify gaps in knowledge to inform future research. The Population, Concept, Context framework (PCC framework; Peters et al., 2020) was used to develop the following research question: What is known from the existing literature regarding trauma-informed care (TIC) approaches in the context of intellectual and/or developmental disabilities (IDD)? More specifically, this scoping review poses five questions: (1) 'In what contexts and with which specific IDD populations have TIC approaches been applied?', (2) 'How has research been conducted on TIC in this field and what is the quality of this research?', (3) 'What are the characteristics of TIC approaches in the context of IDD?' (4) 'What key findings and messages have been reported in the literature exploring TIC in this context?', and (5) 'What are the knowledge gaps regarding TIC in the context of IDD?'

Method

This scoping review followed the Arksey and O'Malley (2005) methodological framework for conducting scoping reviews and is reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR; Tricco et al., 2018) guidance. The Arksey and O'Malley (2005) framework is the most commonly used set of guidelines for undertaking scoping reviews (Pham et al., 2014) and describes an iterative process across five core stages. As recommended, wide-ranging research questions were identified (stage 1) as outlined above, before searching across a broad range of sources to identify the relevant studies (stage 2). Pertinent and justified inclusion and exclusion criteria were developed to inform study selection (stage 3). Data was extracted from included sources using a descriptive-analytic approach (stage 4) and collated, synthesised and reported (stage 5) to provide a thematic narrative report of findings relevant to the review questions and accompanying frequency counts of the overall extent and distribution of sources.

An a-priori protocol was developed using the Joanna Briggs Institute (JBI) best practice guidance for scoping review protocols (Peters et al., 2022) and registered with the Open Science Framework on 2 September 2022 (https://osf.io/muhwc/).

Eligibility Criteria

The PCC framework was utilised to construct clear and pertinent eligibility criteria based on the target population, concept, and context (Peters et al., 2020; Pollock et al., 2023). In line with the objectives of this review, to comprehensively scope what is known about TIC in the context of IDD, the inclusion criteria were kept broad. To be included in the review, papers needed to focus on participants with any condition associated with IDD, including children or adults. Participants could also include the systems around people with IDD, namely parents, families, carers or health and social care services and professionals. This inclusivity was to reflect that systems around people with

IDD are often integral parts of their lives (Shady et al., 2022) and to explore how TIC may be of relevance to these systems. Moreover, TIC is considered a systems-level philosophy applicable to everyone (M. and F. Harris, 2001). The concept of interest was TIC approaches being applied in the context of IDD, and thus papers needed to explicitly state that TIC was the focus to be included. No further scrutiny of TIC definitions was applied at screening stage as scoping the characteristics of TIC approaches in the context of IDD was a key review question. Literature pertaining to any health, education or social care setting were eligible for inclusion as scoping the various settings whereby TIC have been applied in the context of IDD was the focus of one of the review questions.

This scoping review considered a wide range of study designs, including but not limited to, experimental, quasi-experimental, qualitative, and descriptive observational, such as case study, designs. Text and opinion papers were also considered for inclusion. The inclusion of diverse methodologies ensured the primary review question regarding what literature exists was addressed. However, only sources available in English were included due to feasibilities around translation. The inclusive nature of the eligibility criteria ultimately reflected the dearth of literature on the topic and upholds the suitability of scoping review methodology (Munn et al., 2018).

Papers were excluded if they focused on trauma-specific services or trauma-specific psychological interventions due to the aforementioned distinction between TIC approaches and trauma-specific interventions. Textbooks and presentations were also excluded.

Search Strategy

A search of the literature was conducted using the following three databases initially on 11 August 2022, with a further updated search conducted on 27 February 2023: PsycINFO, Web of Science, and PubMed. The analytic strategy, including chosen search terms and databases, were decided following consultation with an experienced librarian. Search terms included a combination of keywords related to TIC and IDD and utilised Boolean operators and truncation: ("trauma informed care" OR "trauma informed practi*" OR "trauma informed approach*") AND ("learning dis*" OR "developmental dis*" OR "mental retardation" OR "intellectual dis*" OR "autism" OR "autism spectrum dis*" OR "autism spectrum cond*" OR "ASD" OR “ASC” OR "attention deficit hyperactivity dis*" OR "ADHD" OR "cerebral palsy" OR "downs syndrome"). The review was limited to articles from January 2000, chosen as the past 20 years has seen the growth of literature around TIC and more recently within IDD contexts. Due to the small number of sources exploring the topic of interest, no further search limitations or filters were applied. The final search results were exported into Zotero. The electronic database search was supplemented by reviewing the reference lists of included studies from full-text screening for relevant papers.

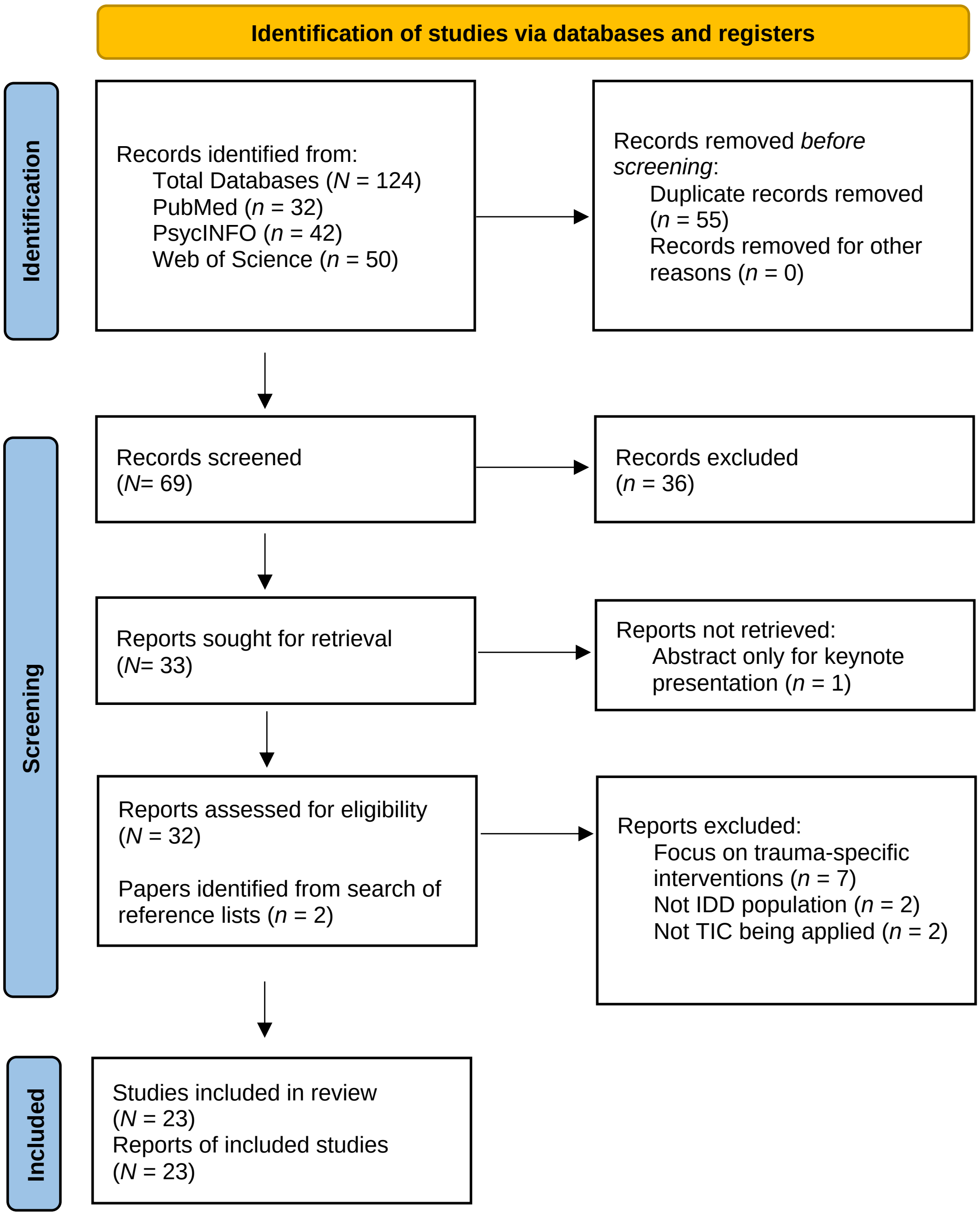
Selection of Sources of Evidence

The searches of the specified databases with the defined search terms identified a total of 124 papers. Once duplicates were removed, the remaining 69 papers were screened at title and abstract against the eligibility criteria by the lead reviewer. To ensure methodological rigour and reduce bias, 20% (n = 11) of the papers from the original search (n = 55) were selected at random using a number generator and screened by a second reviewer. There was an agreement of 90.9% between the two reviewers, representing an inter-rater reliability of kappa = 0.81 and almost perfect agreement (McHugh, 2012). Thus, it was felt the eligibility criteria were well-defined and the second reviewer did not need to review the remaining papers. The single discrepant source was taken forth to full-text screening due to ambiguity of eligibility. Following title and abstract screening, 36 papers were excluded and the remaining 33 were sought to be read in full and assessed in detail against the inclusion criteria. One source was found to be an abstract for a keynote presentation and subsequently excluded. Thirty-two papers were assessed in full for eligibility, with 11 papers cross-checked with the research supervisor due to ambiguities around eligibility and a conclusion on eligibility reached through discussion. Overall, 23 papers met eligibility criteria to be included in the review. The reference lists of included articles were reviewed for additional sources, of which two papers were screened but subsequently excluded.

A PRISMA-ScR flow diagram (Tricco et al., 2018) illustrating the selection process is presented in Figure 2. Reasons for exclusion of papers at full text were recorded and are reported within the diagram.

Figure 2

PRISMA-ScR Flow Diagram of Search and Selection Process



Charting the Data

A data-charting form (Appendix O) was developed in line with the review questions to determine the variables of interest and only extract relevant data from included sources (Pollock et al., 2023). The extracted data comprised context data including article characteristics (i.e., country of origin) and characteristics relating to participants, concept, and context (i.e., IDD population, focus of applying TIC approach, setting). In addition, process data related to each of the review questions were extracted interpretively, including the characteristics of TIC, reported findings and key messages regarding TIC in IDD contexts and the knowledge gaps. The data-charting process endorsed a descriptive-analytic approach to ensure that issues of both context and process were identified, understood, and explained (Arksey & O'Malley, 2005). A data-charting form was completed on Microsoft Word for each paper. Data was charted independently, with inconsistencies or queries checked with the research supervisor.

Critical Appraisal of Included Sources

This review aimed to critically evaluate the characteristics and methodological quality of included research studies using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018). The MMAT (Appendix P) is a critical appraisal tool designed for the appraisal stage of systematic reviews of mixed study empirical research, that is reviews that include qualitative, quantitative, and mixed methods studies. The tool scrutinises the relevance of a study's aim, methodology, study design, data collection, analysis, presentation of findings, author's discussions, and conclusions. While it is typically advised to report each rated criterion individually, for the purpose of this review an overall score was calculated using the mean score of all relevant items of the checklist. Each 'yes' was given a numerical score of 2, 'no' was given a score of 0, and 'can't tell' a score of 1 as followed elsewhere (McNally et al., 2021). There are no cut-off scores for the MMAT to conclude quality of the source, however the chosen scoring allows the reader to consider relative quality of included papers. All included papers were initially screened using the MMAT screening questions to determine if the paper was considered an empirical study (e.g., S1. Are there clear research questions? S2. Do the collected data allow to address the research questions?). As recommended by the tool, if the answer was ‘no’ or ‘can’t tell’ to one or both questions further appraisal using the MMAT was not deemed feasible and such papers were not critically appraised using a tool. Each paper that met criteria for appraisal was critically appraised using the relevant section of the MMAT during the data-charting process and assigned an overall score on the paper’s charting form. Of note, all papers were included and treated equally within the review regardless of quality.

Analysing and Synthesising the Findings

In accordance with the fifth stage of Arksey & O’Malley's (2005) framework, charted data from included papers were collated, analysed, summarised, and reported to provide a thematic narrative synthesis of findings that address the review questions and objectives. Frequency counts of the overall extent and distribution of papers are also provided. This phase of the framework has received scrutiny for lacking clarity (Bradbury-Jones & Aveyard, 2021) and thus being open to researcher bias in the choice of themes, resulting in inconsistencies in the reporting of scoping review findings (Colquhoun et al., 2014; Levac et al., 2010). The novel PAGER framework (Bradbury-Jones et al., 2022) aims to address these shortcomings by providing a standardised approach to analysing, synthesising and reporting scoping review findings, ultimately enhancing methodological rigour. The framework consists of five domains: Patterns, Advances, Gaps, Evidence for practice and Research recommendations (PAGER). The authors have recommended complementary use of the PAGER framework within the fifth stage of the Arksey & O’Malley (2005) framework (Bradbury-Jones et al., 2022). In addition, the PAGER framework ensures the report addresses how the review findings resonate with and inform clinical practice and future research (Bradbury-Jones & Aveyard, 2021). Thus, the PAGER framework was utilised in this review to provide enhanced clarity on the analytic approach and a synthesis that follows coherently.

The analytic process and ensuing synthesis followed Bradbury-Jones et al.'s (2022) proposed PAGER framework methodological process. To provide a macro view of the literature, a basic inductive content analysis of charted data was conducted to generate themes of prominent findings across papers, represented as patterns within the literature. For each pattern, advances were reflected upon in terms of insights that have developed over time and in the most recent findings. The advancements within each pattern illuminated areas that need expanding on from the findings and thus were drawn on to identify gaps in the literature. The patterns, advances, and gaps amongst key findings were synthesised to inform implications and evidence for practice and future research recommendations.

Results

Characteristics of Sources of Evidence

The source's place of origin, sample or context, study design or paper type, and characteristics of TIC are presented in Table 5. Of the 23 included papers, most originated from the USA (*n* = 12), with others undertaken in the UK (*n* = 5), Australia (*n* = 3), Canada (*n* = 2), and India (*n* = 1). Seventeen papers explored the application of TIC in the context of adults with various IDD and their systems. Most of these papers explored TIC within IDD organisations in the USA (Keesler, 2014), including a focus on staff, such as direct support professionals (DSPs; Keesler, 2016, 2017, 2020b, 2020c; Keesler et al., 2023; Keesler & Isham, 2017; Presnell et al., 2022) and IDD service leaders (Rich et al., 2021). A few papers explored TIC in the context of UK Learning Disability services (Goad, 2021) and care staff supporting adults with LD in residential settings (Gregson & Delaney, 2021; McNally et al., 2022; Rye et al., 2021). One paper explored TIC in the context of adults with ASC in UK forensic settings (Faccini & Allely, 2021). The remaining eight papers focused on children and young people, with three papers exploring TIC and ADHD in paediatric practice (Lohr & Jones, 2016; Malhi & Bharti, 2021; T. J. Power et al., 2014). Other papers explored TIC in the context of supporting children with ASC within schools (Berger et al., 2021), young people with ASC seeking acute sexual assault care (Reese & Deutsch, 2020), adolescents with IDD who experience mental health difficulties (Gardiner et al., 2017), young people with spina bifida (Meneses & Cruz, 2017) and parents and support professionals of young people with Prader Willi syndrome (PWS; Schofield et al., 2021).

Just over half of included papers were not empirical studies (*n* = 12), with most described as journal articles (*n* = 6), and a wide range of single paper types including a brief report, case study, case report, scientific letter, viewpoint paper, and a narrative review.

Among all included papers, 15 referenced one specific TIC model, four referenced two models and four papers did not define or elaborate 'trauma-informed care'. More specifically, 14 papers referenced the 'Five core TIC principles' (Fallot & Harris, 2001), with one paper outlining related principles of trust, connection, and safety only. Moreover, four papers referenced the 'Four R's' (SAMHSA, 2014a), one paper referenced SAMHSA's (2014a) TIC principles: (1) creating a collaborative environment, (2) empowerment, voice, and choice, (3) trustworthiness and transparency, and (4) ensuring a safe environment and another the 'Ten implementation domains' (SAMHSA, 2014b). Lastly, one paper described a unique model termed 'TIC' based on principles of recognition, reflexivity, solidarity, and safety. In terms of TIC measures utilised in the empirical studies, two used the 'trauma-informed organisational culture measure' (Waldrop et al., 2010) and two used a updated version of this measure based on Kusmaul et al. (2015). The remaining studies designed surveys and interview schedules based on the abovementioned TIC models.

Critical Appraisal within Sources of Evidence

Of the included papers, 11 met screening criteria for the MMAT and thus were considered empirical studies that could be meaningfully critically appraised using the tool. Five of these were quantitative, four of which were descriptive studies (Keesler, 2017, 2020b, 2020c; Presnell et al., 2022) and one non-randomised trial (T. J. Power et al., 2014), three employed qualitative designs (Keesler, 2016; McNally et al., 2022; Schofield et al., 2021) and three utilised mixed methods (Keesler et al., 2023; Keesler & Isham, 2017; Rich et al., 2021). The full MMAT ratings for these studies are available in Appendix Q, with each studies mean score displayed in Table 5. The overall quality of the empirical studies included in the review is reflected by a total mean appraisal score of 1.85 (range 1.6 – 2), with 7 of the 11 studies achieving a full mean score of 2. Despite papers being included regardless of quality, the mean appraisal score suggests the included empirical studies are of high quality. This included representative samples, adequate data collection methods and conducting appropriate analyses to address the research questions. The main criterion where studies lost points were for not providing a rationale for using a mixed methods design (Keesler & Isham, 2017; Rich et al., 2021), risk of nonresponse bias (Keesler, 2017), and potential confounders unaccounted for in design and analysis and incomplete outcome data (T. J. Power et al., 2014).

Results of Individual Sources of Evidence

Charted data relating to descriptive summaries of the focus of papers, and key findings and messages regarding TIC in the context of IDD reported in the included papers are presented in Table 5.

Table 5

Data Extraction Table

Author(s) / Year / Country	Description of sample / context	Study design / paper type	Focus of paper	Characteristics of TIC referenced / TIC measures used	Main findings / key messages	Quality score (MMAT)
Berger et al. (2021) Australia	TIC practices for children with ASC in schools	Narrative review	Reviewing trauma-informed school-based interventions to explore intersections with school interventions for ASC and potential for TIC school practices	"Four R's" (SAMHSA, 2014a)	- TIC principles overlap with aspects of ASC interventions in schools and using combined framework is recommended - Recommend psychologists and wellbeing professionals support teachers on how they can provide TIC for students with ASC and adverse childhood experiences (ACEs) which could improve teacher mental health literacy, students' wellbeing and reduce teacher burnout	N/A
Faccini & Allely (2021) UK	Individuals with ASC in forensic settings	Journal article	Exploring how to deal with trauma in individuals with ASC through TIC and treatment in forensic settings	Not specified beyond 'trauma-informed care'	- Combination of trauma and ASC has forensic implications, including need to practice consistently with TIC. Specifically, routinely screening for trauma, incorporating trauma history into case conceptualisation, consider traumatic triggers for violent offenses, impact of seclusion or restraint on re-traumatisation and trauma re-enactments with staff	N/A
Gardiner et al. (2017) Canada	Adolescents with IDD who experience mental health difficulties (dual diagnosis)	Journal article	Exploring components of interventions related to attachment and trauma-informed care for adolescents with dual diagnosis to develop an innovative framework to guide assessment and treatment	Five core TIC principles (Fallot and Harris, 2001)	- TIC principles of great relevance to adolescents with dual diagnosis, recommend placing equal emphasis on these integrated with well-validated approaches (e.g., person-centred planning, biopsychosocial assessment) - Innovative care model incorporates TIC as guiding principles (opportunities for choice, collaboration, empowerment, safety, and trustworthiness) from assessment to transition - Hoped to result in improved quality of life and resilience for adolescence with dual diagnosis and their families	N/A
Goad (2021) UK	NHS community Learning Disability team aiming to embrace TIC	Brief report	Reflective account of steps service took to embrace TIC as whole systems approach	Five core TIC principles (Fallot and Harris, 2001)	- When approaching organisational change toward TIC worked alongside all staff to understand hopes and fears by exploring emotional climate and staff understanding of TIC	N/A

					- Collaboratively developed specific identity of TIC for the service, staff, and client group along with shared language around TIC accessible for all - Delivered one-day training for all staff followed by developing shared vision based on organisations tailored model of TIC - Used quick win and long-term goals to measure impact	
Gregson & Delaney (2021) UK	TIC formulation with care staff supporting adults with ID	Case study	A reflective account on embedding TIC within systemic team formulation with care staff to support woman with ID and history of trauma	Principles of trust, connection, and safety	- TIC principles can be embedded within systemic team formulation for adults with ID to explore trauma history and impact on behaviour and relationships with care staff - TIC 'lens' outlined as guiding approach to the intervention to ensure staff recognise importance of connection, safety, and trust for client - Care staff feedback suggests improved understanding of client	N/A
Keesler (2014) USA	TIC in IDD organisations	Journal article	A call for the integration of TIC within organisations supporting people with IDD	Five core TIC principles (Fallot and Harris, 2001)	- Growing awareness of widespread prevalence and impact of trauma amongst IDD populations which calls for integration of TIC in services - Whilst TIC focuses on a cultural shift within organisations, current philosophies of IDD services such as quality of life and person-centred planning could be a good foundation for integrating TIC	N/A
Keesler (2016) USA	DSPs who support adults with IDD (*N* =20)	Qualitative – semi-structured interviews	Exploring staff understanding and perceptions of TIC within a trauma-informed day program	Five core TIC principles (Fallot and Harris, 2001)	- Staff had reasonable understanding of trauma and rich understanding of TIC across five core principles. Importance of TIC was emphasised at individual level, though collaboration highlighted as impactful for staff - Differences between staff related to duration of employment and level of training, with staff requesting additional training - Challenges with TIC emerge at individual, staff, management and interorganisational levels, with resistance at all levels	2

Keesler (2017) USA	DSPs working in IDD services (*N* = 480)	Quantitative – survey	Using trauma-informed perspective to explore the association between individual and organisational factors and the professional quality of life amongst DSPs	Five core TIC principles (Fallot and Harris, 2001) Trauma-informed organisational culture measure (Waldrop et al., 2010)	- 75% of DCPs reported experiencing at least one ACE, with one third of DCPs reporting four or more ACEs - DSPs perception of the presence of five TIC principles within organisation was neutral to favourable - Organisational culture that aligns with TIC was a significant factor in promoting DSPs professional quality of life as measured by compassion satisfaction and reduced burnout	1.6
Keesler (2020b) USA	DSPs working with adults with IDD (*N* = 380)	Quantitative – survey	Exploring the extent to which IDD organisations implement TIC practices with DSPs	Five core TIC principles (Fallot and Harris, 2001) Trauma-informed organisational culture measure (Kusmaul et al., 2015)	- IDD organisations use some practices with DSPs that align with three principles of TIC including DSPs safety in workplace, ability to make a difference and confidentiality in personal information - However, variability and significant differences across the main five TIC principles with safety and empowerment most strongly noted by DSPs and collaboration between DSPs and leadership identified by DSPs as lacking	2
Keesler (2020c) USA	DSPs working with adults with IDD (*N* = 380)	Quantitative – survey	Exploring the relationship between trauma-informed organisational culture and DSPs professional quality of life	Five core TIC principles (Fallot and Harris, 2001) Trauma-informed organisational culture measure (Kusmaul et al., 2015)	- Trauma-informed organisational culture had significant positive impact on DSPs psychological wellbeing associated with increased satisfaction, lower levels of burnout and secondary traumatic stress - Trauma-informed organisational culture had greatest impact on burnout - Collaboration weakest of five TIC principles in relationships between DSP and leadership	2
Keesler & Isham (2017) USA	DSPs (*N* =20) who support adults with IDD (*N* = 16)	Mixed methods – secondary data analysis and interviews	An initial conceptualisation and preliminary assessment of a new trauma-informed day programme to understand the impact on individuals with IDD and care staff	Five core TIC principles (Fallot and Harris, 2001) Trauma-informed organisational culture measure (Waldrop et al., 2010)	- Strong presence of the five core TIC principles within the program - Significant reductions in overall challenging behaviour, aggression, and PRN medication usage, allowing progressive increase in quality of life - DSPs felt they are making a difference, recognised clients progress within the programme, though identified compromising factors that impact delivery of TIC such as breach of trust with management	1.6

Keesler et al. (2023) USA	DSPs in IDD services (*N* = 24)	Mixed methods – survey	The development and pilot evaluation of a digital TIC training for DSPs	Five core TIC principles (Fallot and Harris, 2001) and "Four R's" (SAMHSA, 2014a) – with training content informed by these models	- Digital training associated with improved understanding of trauma for some staff and increased understanding of TIC for most staff, including the five core principles - Following training, some staff demonstrated growth towards TIC, including modifying their approach based on awareness of past trauma influencing current behaviour and an increased alignment with TIC - Majority of participants expressed strong likelihood of utilising TIC and identified organisational strengths and challenges to using TIC	2
Lohr & Jones (2016) USA	Paediatric practice with children in foster care with ADHD symptoms	Special issue journal article	Exploring importance of paediatricians taking a TIC approach when treating children in foster care with trauma histories and recognising increased rates of ADHD	Not specified beyond 'trauma-informed care'	- Paediatricians should draw on TIC to consider impact of trauma history on health and development when working with children in foster care, especially in context of ADHD symptoms - Mental health specialist trained in TIC should also meet with child for comprehensive evaluation - Awareness of complexity and impact of trauma allows paediatricians to consider barriers to care with trauma-informed perspective	N/A
Malhi & Bharti (2021) India	Paediatric practice with children with ADHD symptoms and developmental trauma	Scientific letter	Recognising the potential links between adverse childhood experiences and trauma with symptoms of ADHD in children and indicated need for TIC in paediatric IDD settings	Not specified beyond 'trauma-informed care'	- Trauma-informed management of ADHD should focus on creating safe therapeutic environment and enhancing parent-child attachment - Recommends providing TIC as a developmentally sensitive framework to enhance quality of care - Recommend routine trauma screening when assessing children who present with behaviours that challenge to address erroneous neurodiversity diagnoses	N/A
McConnell & Phelan (2022) Canada	Women with ID who have experienced intimate partner violence	Journal article	To generate preliminary set of guiding principles, including TIC, for social service workers supporting women with ID ending an abusive	Own framework termed 'trauma-informed care' based on principles of recognition, reflexivity, solidarity and safety	- Developed a relational framework for inclusive, trauma-informed services for women with ID aimed at fostering relational autonomy - By enacting relational principles of reflexivity, recognition, solidarity, and safety social workers can support women with ID with safety planning, basic needs, strengthening	N/A

			relationship		relationships, acquiring new skills and nurturing self-respect, self-efficacy and self-esteem	
McNally et al. (2022) UK	Staff in residential services for adults with ID (*N* = 32); care staff (*n* = 8), managers (*n*= 11), and practitioners (*n* = 13)	Qualitative – semi-structured interviews	Exploring the understanding of TIC amongst direct care workers, managers and specialist practitioners working in community residential services for adults with ID	Five core TIC principles (Fallot and Harris, 2001) and "Four R's" (SAMHSA, 2014a)	- Perceptions of TIC and gaps in knowledge highlighted need for staff training in trauma and TIC, enhanced staff support, and TIC implemented at an individual and organisational level - Barriers to implementing TIC included time and resources, staff retention, competing models of care and changing roles of service delivery	2
Meneses & Cruz (2017) USA	Children and youth with spina bifida	Journal article with brief case study	Demonstrating how TIC can promote developmental, behavioural, physical, and mental health by strengthening a developmentally orientated care model for children and youth with spina bifida	"Four R's" (SAMHSA, 2014a)	- Longitudinal and interdisciplinary follow-ups as standard care for children with spina bifida can benefit from TIC approach - Important to acknowledge impact of trauma on brain development and on relationships within family to focus on cultivating secure and supportive relationships - Via case study, recommend that TIC approach provides broader view of understanding health and development for these youth	N/A
Power et al. (2014) USA	Families and children with ADHD in primary care practices (*N* = 72)	Non-randomised, quasi-experimental trial	Evaluating feasibility and acceptability of Partnering to Achieve School Success (PASS) intervention for children with ADHD, including small TIC component	Not specified beyond 'trauma-informed care'	- Found feasibility and acceptability for PASS intervention in primary care for low-income families of children with ADHD - PASS did not differ significantly to treatment-as-usual on any outcome measures - TIC components included importance of shared decision making with family and providing TIC crisis support when needed (rather than onward referrals)	0.8
Presnell et al. (2022) USA	IDD service providers (*N* = 288)	Quantitative – survey	Examining awareness of trauma, familiarity with TIC and existing training that align with TIC amongst IDD service	Five core TIC principles (Fallot and Harris, 2001) and ten implementation domains (SAMHSA, 2014b) – with	- Some alignment with TIC principles, most agreed their organisation determined if clients had trauma history and used TIC support strategies	2

			providers	24-item survey created based on these	- Most agreed employees at organisation may have experienced trauma and that work environment influences job performance - Intentional efforts are required by IDD services to fully embrace TIC	
Reese & Deutsch (2020) USA	Children and youth with DD who have experienced sexual assault victimisation	Case report	Exploring integration of TIC in care of children and youth with DD who have experienced sexual assault victimisation and case presented where care was compromised to highlight challenges and importance of TIC	Five core TIC principles (Fallot and Harris, 2001)	- Requires TIC approach that prioritises preferences and values of survivor and family, adapts to unique communication style and collaboratively engages in decisions to meet their needs - TIC strategies important to prevent and minimise re-traumatisation - Care is compromised by system failures in providing TIC, including gaps in communication around client needs and lack of knowledge around TIC adaptation for youth with ASC	N/A
Rich et al. (2021) USA / Canada	Service leaders across 100 organizations that support individuals with an IDD (*N* = 130)	Mixed methods – survey	Exploring the perspectives of leaders who work in IDD services regarding how well TIC is being integrated into their service system and the barriers faced	Five core TIC principles (Fallot and Harris, 2001) – with 18-item survey created based on these	- Conflicting quantitative findings indicating that leaders felt staff don't fully understand trauma but high level of confidence that organisations were implementing TIC well - Qualitative findings showed a disconnect between leaders' perceived need to implement TIC and how well organisation currently performing. Highlighted importance of implementing TIC on micro, meso and macro levels - Barriers include lack of communication systems for clients and families, lack of knowledge around trauma in clients and systems, and lack of open communication between services	1.6
Rye et al. (2021) UK	NHS Mental Health of Learning Disability Team and staff supporting adults with ID and trauma	Viewpoint paper	Reflections on developing a TIC training programme for care staff which aimed to increase their self-awareness and improve ability to meet the trauma and attachment needs of people they support	Five core TIC principles (Fallot and Harris, 2001)	- Five core TIC principles central to the training and draws on psychodynamic ideas of attachment, splitting and countertransference in an accessible way to care staff - Very positive feedback from attendees so far with anecdotal evidence of effectiveness from colleagues who have observed changing attitudes and approaches to clients with positive effects	N/A

Schofield et al. (2021) Australia	Parents of young people with PWS and professionals (*N* = 14; parents *n* = 8, clinicians *n* = 4, teachers *n* = 2)	Qualitative – semi-structured interviews	Exploring parents and professionals’ views on behavioural challenges and support strategies to investigate whether TIC principles can be used to improve support for young people aged 12-21 with PWS	“Four R’s” (SAMHSA, 2014a)	- Behaviour support for young people with PWS mapped onto a TIC framework (collaborative environment, empowerment voice and choice, trustworthiness, and transparency, and ensuring a safe environment) - TIC alone did not sufficiently describe all themes, additional novel domains specifically related to PWS phenotype (behavioural underpinnings, modifying the environment and family capacity building) required to fully understand complexities of positive behaviour support	2

Synthesis of Results

The PAGER framework (Bradbury-Jones et al., 2022) was utilised to synthesise the results into a rigorous and coherent narrative. Following an inductive and descriptive content analysis of the main findings and key messages from each included paper, four main patterns were identified: (1) opportunities for embedding TIC within IDD contexts, (2) incorporating TIC principles into specific IDD service models, (3) consideration and implementation of TIC across micro, meso and macro levels, and (4) challenges and barriers to implementing TIC in IDD organisations. Each pattern will be outlined in turn, along with related advances and gaps in knowledge to synthesise the key findings uncovered in this scoping review. The relating evidence for practice and research recommendations of each pattern will be expanded on in the discussion. An overview of the PAGER synthesis is depicted in Table 6.

Pattern 1: Opportunities for Embedding TIC within IDD Contexts

The earliest paper included in this review (Keesler, 2014) proposed that existing philosophies underpinning IDD services, such as person-centred care and a focus on quality of life, could provide a strong foundation for integrating TIC within IDD organisations. That is, TIC *"in essence fosters the same values and philosophies yet extends them to staff and individuals alike, while acknowledging the potential impact of trauma and demonstrating sensitivity to triggering events and stimuli in the lives of both"* (Keesler, 2014, p. 40). Thus suggesting that TIC overlaps with practices utilised within IDD organisations generally, whilst offering something additional by considering the likelihood of and sensitivity to trauma among both individuals and staff. Most recently and consistent with such conclusions, Keesler et al. (2023) found that the majority of a small sample of DSPs reported strengths of IDD services for facilitating TIC, with half of participants indicating alignment between TIC and aspects of their organisations culture and training. Similarly, Goad (2021) postulated that TIC is consistent with and compliments various priorities within learning disability services, such as agendas to reduce hospital admissions, reducing restrictive practices and promoting staff wellbeing. However, presence of the five core TIC principles within IDD organisations has been rated as neutral by a large sample of DSPs (Keesler, 2017). Further enquiry by Keesler (2020b) from DSPs' perspectives found that only two TIC principles, safety and empowerment, were used ordinarily with staff in just three routine practices; focus on DSPs safety in the workplace, opportunities to make a difference in their work, and confidentiality of personal information. Moreover, Presnell et al. (2022) explored alignment between IDD service providers and TIC in regard to organisational practices endorsed. Alike Keesler's (2020b) findings, staff reported limited alignment with TIC principles, for example only half of participants indicated that support plans often or always included client's trauma context and provided TIC support strategies. Both studies therefore concluded that IDD organisations ought to make intentional efforts to more fully embrace TIC through explicit and comprehensive initiatives for staff and the individuals they support.

In addition, substantial overlap has been reported between TIC and school-based practices for children with ASC (Berger et al., 2021) and behavioural interventions for young people with PWS (Schofield et al., 2021). More specifically, Schofield et al. (2021) qualitatively explored parents and professionals' perspectives on the behavioural challenges faced by young people with PWS and related support strategies to examine alignment with TIC. Perceived strategies could be mapped closely onto a TIC framework, including: (1) creating a collaborative environment, (2) empowerment, voice, and choice, (3) trustworthiness and transparency, and (4) ensuring a safe environment. However, the authors found that TIC alone did not sufficiently describe all themes, necessitating additional novel domains specifically related to the PWS phenotype (behavioural underpinnings, modifying the environment and family capacity building) to fully encompass the complexities of behaviour support for these young people. This study advances other findings by suggesting that TIC provides a relevant foundation, but specific and enhanced frameworks beyond core TIC principles may be recommended for various IDD populations. This conclusion was supported by Reese & Deutsch (2020) who proposed that a uniform TIC approach is challenging with IDD populations, and instead professionals should consider preferences and values of the individual, and adapt or extend TIC approach accordingly.

In summary, this pattern encapsulates initial conclusions and more recent consistent findings in the literature that there are opportunities for TIC and overlaps with existing philosophies within IDD services, though intentional efforts are required by organisations to fully implement TIC. Advances in the literature recommend developing specific TIC frameworks for particular IDD characteristics and related support needs, linked to the next identified pattern regarding implementing TIC in specific IDD contexts.

Pattern 2: Incorporating TIC Principles into Specific IDD Service Models

Many of the included papers described ways in which TIC has been or could be incorporated into guiding principles and service models within specific IDD services. A few papers (Lohr & Jones, 2016; Malhi & Bharti, 2021; T. J. Power et al., 2014) promoted the importance of drawing on TIC in paediatric practice supporting children with ADHD symptoms, highlighting the potential link between trauma and neurodevelopmental outcomes. Similarly, Meneses and Cruz (2017) emphasised that TIC acknowledges the impact of trauma on brain development and can strengthen a developmentally-orientated care model for children with spina bifida. The brief case study demonstrated that a TIC approach provided a richer understanding of health and development for these children and proposed routine care practices could benefit from incorporating TIC principles. Similarly, the potential for incorporating TIC was reported within practices in schools for young people with ASC (Berger et al., 2021) and services supporting neurodiverse young people who have experienced sexual assault victimisation (Reese & Deutsch, 2020). Moreover, Faccini & Allely (2021) proposed TIC guidelines for adults with ASC within forensic settings, including: routinely screening for trauma, incorporating an individual’s trauma history into formulation, considering traumatic triggers for violent offences, and aiming to prevent re-traumatisation within practices such as seclusion.

In addition, innovative models comprising TIC were described in settings for adolescents with IDD and mental health difficulties (Gardiner et al., 2017), women with ID who have experienced intimate partner violence (McConnell & Phelan, 2022), to optimise behaviour support for young people with PWS (Schofield et al., 2021), as well as within team formulation interventions (Gregson & Delaney, 2021) and training for care staff (Rye et al., 2021) provided by LD services. More specifically as an example, Rye et al. (2021) described the development and delivery of a tailored TIC training for care staff supporting adults with ID and complex trauma. The training explored psychodynamic concepts of attachment, splitting and countertransference, whilst embodying the five core TIC principles, to enhance staff members' understanding of trauma and promote trauma-informed practice. The authors reported positive feedback from attendees and initial anecdotal evidence of effectiveness from colleague observations of positive effects on changing attitudes and approaches to clients. These anecdotal outcomes offered an advancement to most included papers that did not include evaluation, with further research evidently being developed to evaluate this approach (Rye et al., 2021). Thus, identified gaps within this pattern related to a lack of set indicators of impact or change to evaluate feasibility and effectiveness of incorporating TIC. Importantly, there has been no input or feedback from the perspectives of individuals with IDD themselves nor their families.

Pattern 3: Implementing TIC across Micro, Meso and Macro levels

Some papers emphasised the importance of considering and implementing TIC across micro, meso, and macro levels within IDD contexts. On the micro level, the importance of TIC for individuals and staff alike was highlighted (Keesler, 2014), with numerous papers acknowledging that supporting staff is an essential part of TIC in IDD contexts (Goad, 2021; McNally et al., 2022). However, staff tended to acknowledge the significance of TIC for individuals they support, with few recognising the intended impact among employees (Keesler, 2016; McNally et al., 2022). Moreover, whilst 96% of DSPs agreed their organisations used TIC with clients, only half the amount from the same sample agreed that TIC was utilised with employees (Keesler et al., 2023). Keesler (2017) emphasised the relevance of TIC for staff by establishing that 75% of DSPs have experienced at least one ACE, with one third reporting they had experienced four or more ACEs. Similarly, around 78% of a different sample of staff, including DSPs, agreed that employees may have experienced trauma, with 92% agreeing that employee trauma can be triggered by aspects of the job and impact job performance (Presnell et al., 2022). Such findings suggest that TIC principles are of relevance to staff members' personal and professional experiences, therefore TIC should be explicitly considered and implemented in relation to staff at the micro level.

Further implications of TIC for staff were reported at the meso level, including collaboration with management highlighted as a particularly relevant component of TIC for staff (Keesler, 2016, 2020b, 2020c). Of note, these studies reported that DSPs felt collaboration with their employer was often lacking and thus identified as a TIC principle rarely being implemented within IDD organisations. Further highlighting the importance of collaboration among all staff when implementing TIC, Goad (2021) described their organisation's journey to embracing TIC as a whole systems approach. The approach embraced collaboration and empowerment with staff by developing a collaborative identity and vision of TIC for the organisation whereby all staff voices were invited and included. More broadly, the authors posited that TIC offers organisations an umbrella framework, which if implemented at the meso level can connect multiple service agendas and provide actions along with relational positions for system wide trauma-informed change. Thus, suggesting that IDD services can formulate their own TIC visionary model to implement as a unique organisational culture. Moreover, TIC training programmes for care staff have been developed to promote the implementation of trauma-informed practices (Keesler et al., 2023; Rye et al., 2021). The most recent paper in this review was a pilot study by Keesler et al. (2023) exploring a novel digital TIC training for DSPs employed by a large IDD organisation in the USA, which was found to be associated with increased understanding of and alignment with TIC practices amongst staff.

Linked with this, Keesler and Isham (2017) examined one organisation's innovative trauma-informed day programme for adults with IDD who had recently been deinstitutionalised. Conceptually, the program aimed to apply the five core TIC principles across staff and individuals' experiences, for example nurturing trust by encouraging staff to make decisions without relying on hierarchical processes and fostering active listening by staff for clients to develop trust. This study is the only included paper to assess the impact of implementing TIC at the meso level on both staff and individuals. Findings indicated a strong presence of all core TIC principles and associated significant reductions in overall challenging behaviour, aggression, and PRN medication usage, thus promoting progressive increase in quality of life amongst individuals with IDD. In addition, staff satisfaction was indicated through qualitative data from staff recognising clients' progress within the programme and that they make a positive difference (Keesler & Isham, 2017). Advances in this area of impact on staff are offered by Keesler's (2017, 2020b) papers demonstrating that TIC organisational culture, whereby TIC was implemented across micro and meso levels, was associated with staff satisfaction and greater wellbeing. Thus, emerging evidence suggests that trauma-informed organisational culture promotes DSPs' professional quality of life as indicated by compassion satisfaction and reduced burnout (Keesler, 2017). Similarly, presence of TIC had significant positive impacts on DSPs psychological wellbeing, including increased satisfaction and lower levels of burnout and secondary traumatic stress (Keesler, 2020c). Though, gaps remain regarding the long-term impact of TIC culture on staff wellbeing and associated influences on staff retention. It is also unknown whether there is any indirect impact of enhanced professional quality of life and staff wellbeing on outcomes for individuals with IDD.

In terms of the macro level, only one study exploring perspectives of IDD service leaders spoke to TIC at the policy and community level (Rich et al., 2021). The findings suggested that organisations should nurture ongoing partnerships with other agencies to promote consistency, as well as reallocate funds across policies to prioritise TIC. Moreover, participants spoke to the culture shift needed on a societal level to recognise the equal worth and rights of individuals with IDD and the importance of combating stigma when considering TIC in IDD contexts. However, generally there appeared to be a gap regarding further elaboration on TIC more broadly beyond IDD organisations, such as what constitutes TIC at the macro level for this context and the impact of such implementation on outcomes for organisations and those served.

Pattern 4: Challenges and Barriers to Implementing TIC in IDD Organisations

Included papers identified various challenges and barriers to implementing TIC within IDD contexts across the micro, meso and macro levels (Keesler, 2016; Rich et al., 2021). On the micro level, staff reported that they felt individuals they worked with had difficulty adjusting to being supported in line with a TIC approach, perhaps due to stark contrast to their previous experiences within institutions (Keesler, 2016). For example, it was suggested that the emphasis on choice offered by TIC might increase anxiety amongst individuals due to familiarity with structure enforced in institutions. Leaders of IDD organisations reported difficulties communicating and apprehensions around disclosing on the part of the person with IDD and their family as further barriers at this level (Rich et al., 2021). In relation to staff, challenges were noted around ensuring fidelity of adopting a TIC approach, with inconsistent attitudes across staff (Keesler et al., 2023; Keesler & Isham, 2017) and some staff working in ways counterproductive to TIC (Keesler, 2016). Linked with this, a commonly reported barrier related to lack of training, and thus knowledge and skills, amongst staff regarding both trauma and TIC (Keesler et al., 2023; McNally et al., 2022; Presnell et al., 2022; Rich et al., 2021).

Some papers identified the need for further training on TIC for staff who support individuals with IDD, due to both an established lack of training leading to limited knowledge and understanding of TIC amongst staff (Keesler, 2016; McNally et al., 2022; Presnell et al., 2022; Rich et al., 2021) and direct requests by staff (Keesler, 2016; Presnell et al., 2022). For example, Presnell et al. (2022) found that only 17% of participants, who were a mix of DSPs, clinicians, and managers, reported their agencies providing TIC-specific training, which was often not required for all staff. Moreover, 74% of participants indicated that they would like to learn more about TIC. A couple of included papers have begun to advance this area by exploring and provisionally evaluating TIC training for staff in IDD contexts (Keesler et al., 2023; Rye et al., 2021).

At the meso level, Keesler (2016) highlighted challenges flattening the hierarchy between staff and management and a perceived lack of support from management by staff as impediments to

TIC within IDD organisations. Similarly, breaches of trust between staff and management were reported as going against TIC and negatively impacting implementation of TIC organisational culture (Keesler & Isham, 2017). In addition, implementing TIC was reportedly compromised by systemic failures to acknowledge individuals' specific needs and gaps in communication (Keesler et al., 2023; Reese & Deutsch, 2020). Similarly, McNally et al. (2022) and Presnell et al. (2022) reported lack of time and resources as potential barriers to TIC identified by staff within IDD organisations, linked with lack of vision and patience in the context of competing models of care and adjustment to culture shift (Rich et al., 2021). Finally, a few papers reported challenges with staff recruitment and retention in IDD organisations as key barriers to TIC (McNally et al., 2022; Presnell et al., 2022; Rich et al., 2021). That is, as DSPs in Keesler et al.'s (2023) study described, IDD services are short staffed, face high staff turnover and even higher burnout amongst staff, which ultimately hinder utilisation of TIC.

Challenges identified at the macro level included perceived resistance from other agencies (Keesler, 2016) and fragmentation of services, which leads to lack of open communication between services and impedes consistency (Keesler et al., 2023; Rich et al., 2021). In addition, Rich et al. (2021) highlighted wider cultural barriers within IDD field itself, such as the lack of fit between TIC and a medical model understanding of disability. That is, IDD service leaders proposed the dominant medical model can cause diagnostic overshadowing and thus opposes TIC by attributing behaviours to disability rather than symptoms of trauma. Though ultimately, findings identifying challenges across the various levels lacked quantifiable and validated tools to assess and identify gaps in knowledge, attitudes, and practices, as well as the related barriers.

Table 6

Synthesis of Results using PAGER Framework (Bradbury-Jones et al., 2022)

Pattern	Advances	Gaps	Evidence for practice	Research recommendations
Opportunities for Embedding TIC within IDD Contexts	Findings progressively suggest despite overlap and opportunities for TIC, IDD organisations need to make intentional efforts and develop specific TIC approaches for various IDD populations	There is need for ongoing empirical work exploring how best to implement TIC approaches for various IDD populations There is a lack of clarity and consistency around what constitutes TIC	Evidence to emerge from future research	Research is needed that explores the implementation of TIC using clear, quantifiable, and comparable measures of TIC and the impact
Incorporating TIC Principles into Specific IDD Service Models	There is a growing body of literature reporting various IDD services adopting TIC principles into service models, including within paediatric practice for various IDD and TIC training delivered by IDD services to care staff supporting adults with IDD and complex trauma	There is a paucity of qualitative or participatory research regarding people with IDD perspectives on and experiences of TIC There is a lack of outcome research evaluating feasibility and effectiveness of TIC frameworks	Emerging practice-based evidence, including local TIC training models with staff teams to enhance understanding of trauma and promote TIC practices	To conduct quantitative research to evaluate TIC To carry out research exploring the views, experiences and needs of individuals with IDD and their families in relation to TIC
Implementing TIC across Micro, Meso, and Macro Levels	Understandings about the implications of TIC for staff has improved, including emerging evidence of positive impacts of organisational TIC culture on staff Emerging models of TIC training for staff within IDD contexts	There is limited understanding about the long-term implications of TIC, including outcomes for staff and people with IDD There is a lack of understanding about TIC at the macro level	It is important that IDD organisations consider TIC across all levels Staff likely benefit from TIC organisational culture	To carry out longitudinal research exploring the impact of TIC cultures on outcomes across organisations, including for direct care staff and other professionals Further develop and evaluate TIC training
Challenges and Barriers to Implementing TIC in IDD Organisations	There is a growing body of literature about the barriers to adopting TIC, particularly regarding TIC training and knowledge amongst staff and challenges with high staff turnover	Lack of validated tools to assess gaps in knowledge, attitude and practices and identify related barriers There was a gap in understanding around challenges of TIC from the perspective of people with IDD and their families	It is likely important that care staff have TIC training opportunities Further evidence to emerge from future research	Studies are required that use validated indicators of change or develop specific IDD tools to evaluate effectiveness and more robustly explore barriers to implementation, including people with IDDs' perspectives in the research

Discussion

There has been a significant increase in trauma-related research over the past decade for individuals diagnosed with IDD (Didden & Mevissen, 2022), though this has lagged compared to general population research. Likewise, there has been enthusiasm for the development of TIC over the past 20 years, though little of the research exploring TIC has considered the well-indicated implementation within services for individuals with IDD. To date there has been no robust and systematic review of the literature to determine what does exist regarding TIC implemented within IDD contexts. Therefore, the aim of this scoping review was to scope, map and synthesise the relevant literature to establish 'What is known from the existing literature regarding TIC approaches in the context of IDD?'. More specifically, this review hoped to address, (1) 'In what contexts and with which specific IDD populations have TIC approaches been applied?', (2) 'How has research been conducted on TIC in this field and what is the quality of this research?', (3) 'What are the characteristics of TIC approaches in the context of IDD?' (4) 'What key findings and messages have been reported in the literature exploring TIC in this context?', and (5) 'What are the knowledge gaps regarding TIC in the context of IDD?'. The findings of the review will be discussed in relation to broader TIC literature, with the evidence for practice, knowledge gaps, and research recommendations presented for each identified pattern of findings, followed by the strengths and limitations of the review.

The results of this scoping review elucidated that TIC approaches are beginning to be implemented across a range of IDD settings that serve both adults and children. Since calling for the integration of TIC within IDD settings in 2014 (Keesler, 2014), the included papers in this review suggest the past decade has seen TIC be applied within adult IDD organisations, including IDD services in the USA (Keesler, 2016, 2017, 2020b, 2020c; Keesler et al., 2023; Keesler & Isham, 2017; Presnell et al., 2022; Rich et al., 2021) and learning disability services in the UK (Goad, 2021; Gregson & Delaney, 2021; McNally et al., 2022; Rye et al., 2021). Notably, most papers that explored TIC within paediatric settings focused on specific IDD such as ADHD (Lohr & Jones, 2016; Malhi & Bharti, 2021; T. J. Power et al., 2014), ASC (Reese & Deutsch, 2020), spina bfida (Meneses & Cruz, 2017), and PWS (Schofield et al., 2021), with one paper focusing on adolescence with IDD (Gardiner et al., 2017). Whereas for adults, papers appeared to focus on individuals diagnosed with learning disabilities or IDD more generally and did not explicitly specify particular IDD. This may be due to the nature of IDD services for adults, for example learning disability services in the UK will support people with an ID and co-occurring DD, such as Down Syndrome and ASC (Schalock et al., 2019). Though, such services require individuals to meet criteria for an ID to be eligible, with those whose difficulties are described as DDs, such as ASC without associated or co-occurring ID deemed ineligible. Only one included paper focused on adults with ASC-only in forensic settings (Faccini & Allely, 2021). Thus, a gap in the TIC and IDD literature and area for future research is within organisations for neurodiverse individuals who are diagnosed with DDs but not an ID, and how TIC may be implemented for this population. Furthermore, just one paper explored TIC within educational settings for children with ASC (Berger et al., 2021), which is surprising given the progressive literature on trauma-informed approaches in education (M. S. Thomas et al., 2019). Therefore, there is also a gap and avenue for future research regarding TIC in specialist education services, including schools and colleges for individuals with IDD.

Eleven of the included papers were considered empirical studies, with the remaining 12 papers comprising a range of source types, predominantly journal articles. The empirical studies that researched TIC in the context of IDD were conducted utilising a range of quantitative, qualitative, and mixed methods. Though the overall quality of the research as appraised by the MMAT was considered to be high, there are further considerations in terms of methodological shortcomings of the included studies. Firstly, most of the quantitative studies were observational in nature and utilised cross-sectional survey data (Keesler, 2017, 2020b, 2020c; Presnell et al., 2022), which both prevents causal inferences to be drawn and poses risks of self-report bias. For example, DSPs' subjective interpretation of the extent to which TIC is implemented may differ from a more objective measure and other professionals' perceptions (Unick et al., 2019). Furthermore, the psychometric properties of the TIC organisational culture measures used in four of the studies (Keesler, 2017, 2020b, 2020c; Keesler & Isham, 2017) are not well-validated and thus it is unclear if the measures truly reflect Harris and Fallot's (2001) five principles of TIC as intended. One paper employed a non-randomised trial, however 'TIC' was a trivial component of the multimodal intervention and thus the findings were not elaborated in this review (T. J. Power et al., 2014). Such methodological considerations briefly speak to the overall quality of research in this area and are important to hold in mind when interpreting the findings of this review. However, scoping reviews do not typically provide in depth critical evaluation of methodology as the aim is to scope what is known regardless of quality (Pollock et al., 2023). Though the dearth of available empirical research in this area does helpfully illuminate that further research is required before a systematic review would be warranted (Tricco et al., 2018).

Notably, the ways in which TIC was conceptualised among the included papers was diverse, though tended to focus on the five core TIC principles (Harris & Fallot, 2001) and four Rs model of TIC (SAMHSA, 2014a). One paper referenced the SAMHSA (2014b) ten implementation domains for TIC alongside the five core principles and created a survey based on these (Presnell et al., 2022). This model encompasses organisational change literature and other TIC models to provide organisations with a ten-step guide (for example, steps for organisational leadership, training and workforce development, and evaluation) toward TIC culture shifts. Four papers did not define or elaborate on what was meant by implementing 'trauma-informed care' (Faccini & Allely, 2021; Lohr & Jones, 2016; Malhi & Bharti, 2021; T. J. Power et al., 2014), which problematically contributes to unclear and inconsistent reporting of TIC applications also found in the wider literature (Sweeney & Taggart, 2018). The state of the literature is such that currently TIC is briefly defined by conceptual models rather than specific detail of TIC characteristics. These findings emphasise the heterogeneous nature of how TIC is represented in the literature, which may impede meaningfully interpreting and comparing the implementation of TIC. Thus, it will be important that researchers consider the conceptualisation of TIC when conducting future research as not to hinder the progress of this field.

The first key finding of this review was that there appears to be opportunities for embedding TIC within IDD contexts. Some papers acknowledged the overlap of TIC principles with philosophies of IDD organisations, such as the well-documented focus on person-centred care and self-determination (Pinals et al., 2022a), and thus proposed such services have a strong foundation for integrating TIC (Goad, 2021; Keesler, 2014; Keesler et al., 2023). Though, as warned in psychiatric practice settings, it may be that in fact TIC presents a radical shift even in contexts where TIC would appear innate and basic good practice (Isobel, 2016). In line with this, further findings posited that intentional efforts are required to fully embrace TIC in its entirety (Keesler, 2020b; Presnell et al., 2022). This included more specific thought around how TIC can be implemented for specific IDD populations and organisations, for example particular considerations around experiences of young people with PWS (Schofield et al., 2021). Thus, future enquiry may benefit from empirically exploring how specific TIC principles link to outcomes for various IDD populations, such as studies that have explored opportunities for choice and links to self-determination in adults with IDD (Jones et al., 2018).

At the broader organisational level, the included paper by Goad (2021) proposed a process for developing and implementing specific TIC visionary models for unique service contexts. Though there remains a lack of clarity, consistency, and guidance with regards to implementing the various facets of TIC in IDD settings. This speaks to a gap in the literature and avenue for future research to explore the implementation of TIC using clear, measurable, and comparable frameworks of TIC and empirically evaluate the impact. Interestingly, a new study by McNally et al. (2023) published after this review was conducted speaks to this by co-producing a TIC framework within residential services for adults with an ID and an associated logic model to clarify the mechanisms of change. However, whilst the framework was shaped by relevant evidence bases, it is yet to be operationalised and evaluated. Ongoing research following suit will help to provide clear and evidence-based guidance on how best to implement TIC approaches at various levels within IDD organisations.

The next interconnected key finding from this review was that TIC principles have been incorporated in specific IDD service models. For example, a few papers referenced using TIC within paediatric settings (Lohr & Jones, 2016; Malhi & Bharti, 2021; Meneses & Cruz, 2017; T. J. Power et al., 2014) to recognise the widely acknowledged potential impact of trauma on neurodevelopmental outcomes (Hoover, 2020). Though such papers did not provide detail beyond stating TIC was being applied. However, preliminary practice-based evidence was offered within adult learning disability contexts by Rye et al. (2021) around a specific TIC training model for care staff teams using psychodynamic concepts to enhance understanding of trauma and promote TIC practices, which was reported to have positive impacts on care staff and clients. Though largely, such included papers did not provide empirical evidence for practice. This lack of empirical research appears to follow a similar trend to the broader TIC literature, where noted uses are fast emerging but rigorous evaluation of the effectiveness has lagged (Hanson & Lang, 2016). Likewise, the lack of feedback from people with IDD themselves regarding TIC reflects the lack of client voice amongst the TIC movement more broadly (Becker-Blease, 2017). However, trauma-informed approaches have been identified as an important priority by people with ASC (Benevides et al., 2020) and people with learning disabilities (Weise et al., 2018). Thus, further participatory research regarding people with IDDs' perspectives on and experiences of receiving TIC, as well as related implementation research evaluating feasibility and effectiveness of TIC frameworks is required. For example, priorities for future research may include understanding the impact of TIC on clients' perceptions of care and the mechanisms through which changes in staff practices around TIC influence client outcomes.

Relatedly, the third key finding from this review was that TIC should be implemented beyond the individual with IDD and across micro, meso, and macro levels of IDD organisations. This finding is supported by broader TIC literature (Fernández et al., 2023), which suggests whole organisation change produces the most significant outcomes (Purtle, 2020) and ensures positive impacts for both service users and staff (Hales et al., 2019). At the micro level, studies included in this review reinforced the importance of TIC in relation to staff by revealing that high proportions of care staff have experienced trauma (Keesler, 2017; Presnell et al., 2022). Though alike findings among the broader TIC literature (Wolf et al., 2014), staff members were largely unaware of the relevance of TIC as it relates to being an employee (Keesler, 2016; McNally et al., 2022). Moreover, the findings of this review suggest that TIC is often not being considered or implemented with employees (Keesler et al., 2023). Thus, it will be important to find ways to share the links more explicitly between TIC and all levels of organisations, including the intended relevance for staff members. For example, by incorporating TIC practices for employees within staff policies and initiatives, and perhaps training for managers around TIC as it applies to staff. The marketability of such approaches is strengthened by related research revealing the particular prevalence and impact of job stress, burnout, and dissatisfaction of care staff in this sector (Ryan et al., 2021; Søndenaa et al., 2015). Moreover, research has suggested that there are likely bi-directional influences of promoting staff support and wellbeing on quality and continuity of care for individuals with IDD (Shead et al., 2016). That is, supporting the longevity of care staff affords opportunities for continuity of care for individuals, whilst also decreasing organisational expenditures associated with staff turnover (Keesler, 2017). Ultimately, these findings suggest that TIC is best embraced as a whole systems approach to underpin organisational culture, which includes considering the experiences and needs of employees. Interestingly, most included papers focused on DSP’s, which is the equivalent of care staff in the UK, with only one paper including other professionals who work closely with people with IDD (McNally et al., 2022). Thus, there is a gap in understanding of both the relevance of TIC for, and experiences of, other professionals such as nurses, social workers, psychologists, and managers. Future research should therefore further explore TIC at the micro and meso levels in relation to all employees within IDD organisations.

The findings of this review revealed that there is emerging evidence of positive outcomes following the implementation of trauma-informed organisational practices on care staffs’ experiences at work. This provides preliminary evidence for practice that staff likely benefit from TIC organisational culture in terms of their wellbeing and job satisfaction (Keesler, 2017, 2020c; Keesler

& Isham, 2017) and thus IDD organisations ought to consider implementing TIC at the meso level. A possible explanation for this finding is that workplace culture can buffer the impact of stressful work situations, such as supporting individuals displaying behaviours that challenge (Broadhurst & Mansell, 2007). However, further empirical investigation is required to explore this link and the effectiveness of TIC organisational culture more widely. Future research could benefit from utilising TIC systems measures used within the broader TIC literature (Champine et al., 2019, 2022). Relatedly, there is limited understanding regarding the long-term implications of TIC organisational cultures. Thus, recommendations for future research include carrying out longitudinal research to explore the impact of TIC culture on outcomes across organisations, including for various employees and recipients of services. In addition, the findings identified gaps and resulting needs for research exploring what constitutes TIC at the macro level for this context and the impact of such implementation on outcomes for organisations and those served.

Lastly, this review identified an array of challenges and barriers to implementing TIC within IDD contexts. A commonly reported barrier to implementing TIC was the limited TIC knowledge among care staff who work closely to support people with IDD (Keesler et al., 2023; McNally et al., 2022; Presnell et al., 2022; Rich et al., 2021). Many papers alluded to the fact that this is unsurprising given the pervasive lack of trauma related training provided for these roles (Keesler, 2016). Thus, according to Treisman's (2018) river model of TIC implementation, most care staff were reportedly in the position of being trauma aware, which is upstream to and a precursor of being trauma informed. Of note, care staff also commonly requested further TIC training from their organisations (Keesler, 2016; Presnell et al., 2022). Consequently, these papers emphasised the need for further training opportunities for staff around trauma and TIC. Though, just two included papers explored training, only one of which empirically explored a TIC focused training programme delivered online for staff members (Keesler et al., 2023). This highlights both an emerging area of research and a gap regarding TIC training programmes and related empirical evaluation. Though preliminary findings provide tentative evidence for practice that staff benefit from and should be provided with TIC training. This is further emphasised by findings of positive effects from TIC staff training among the broader literature within adult mental health settings (Palfrey et al., 2019; Purtle, 2020). However, individuals with IDD rely heavily on care staff and are at high risk of trauma inflicted by such staff (J. Collins & Murphy, 2022), therefore there is arguably a particular importance for these settings to invest in TIC training. Hence, ongoing research is required to further develop and evaluate specific TIC training for IDD service employees at all levels, though importantly this would likely be most meaningful alongside broader organisational culture change which is required to become trauma-informed (Cook & Hole, 2021).

Relatedly, included papers emphasised challenges related to promoting such organisational culture change (Keesler et al., 2023; Rich et al., 2021) and barriers associated with lack of resources, such as staff shortages (McNally et al., 2022; Presnell et al., 2022; Rich et al., 2021), which impedes the implementation of TIC at all levels. The challenges of implementing TIC elucidated by the current review are not entirely unique to IDD settings and align with reported challenges among the broader TIC literature (Mihelicova et al., 2018; Roberts et al., 2023). That is, combining the challenges identified within this review, there are inconsistent understandings of what constitutes TIC, and complexities when translating TIC to specific settings, facilitating system level change, and evaluating the implementation of TIC (SAMHSA, 2014a). Indeed, implementation science speaks to the complex processes associated with implementing systemic culture change as it relates to TIC (Mahon, 2022). Thus, future research is required to examine barriers to implementation more robustly using validated measures of attitudes towards TIC (Baker et al., 2016, 2021) and gaps in TIC knowledge and practice (King et al., 2019) within IDD organisations. Ultimately, though some of the findings of this review overlap with the broader TIC literature, it will be important that future TIC research and related policies inclusively consider the IDD field. That is, often individuals with IDD are excluded within trauma policy, guidance and research (D. Morris, 2021), which can ultimately lead to unjust and problematic systemic inequalities (Ramsey et al., 2022).

Strengths and Limitations of the Review

This is the first known review of TIC approaches within organisations that provide services for individuals diagnosed with IDD. The topic area is arguably a priority in current research as it aligns with various topical initiatives and policy drivers to deliver more trauma-informed services for this population (Houck & Dracobly, 2023b; Pinals et al., 2022b). Thus, this scoping review provides a valuable comprehensive examination of what is known from the existing literature in this area and was conducted using systematic and rigorous methodology (Arksey & O’Malley, 2005). Moreover, the protocol for the review was published to allow for transparency and replication. This review also included literature focused on both adults and children, which allows for a lifespan perspective on the implementation of TIC. The findings were synthesised and reported using the novel PAGER framework to improve the coherence of synthesis and implications for practice and research (Bradbury-Jones & Aveyard, 2021). Lastly, this paper was reported in line with PRISMA-ScR reporting guidance to uphold reporting quality (Tricco et al., 2018).

There are limitations to this scoping review that should be considered when interpreting the findings. Firstly, the decisions made about how to analyse and organise the papers are likely to reflect the researcher’s interpretation of the valuable, pertinent, and meaningful aspects within the literature under review. Though, recognising the limitations this brings, transparency has been provided for all methodological decisions, and the PRISMA-ScR protocol and reporting items reduces the potential for researcher bias. Relatedly, the majority of this review was conducted by a single researcher, though a team approach is ideally advised as best-practice to promote rigour and reduce bias (Pollock et al., 2023). However, to mitigate this the researcher met regularly with the research supervisor to discuss and reflect on all phases of the research process, and a second reviewer was utilised during abstract screening for inter-rater reliability checks and to trial the eligibility criteria. Of note, it was not feasible to conduct inter-rater reliability checks for the MMAT and thus the overall mean quality appraisal score is based on the researcher’s ratings alone. Though, the complete MMAT item ratings are displayed in Appendix Q for transparency and studies were included regardless of their score, which was mainly provided for the benefit of readers to give a general sense of the quality for the empirical research in this area.

In addition, a considerable challenge was defining and conceptualising TIC for people with IDD in the eligibility criteria to capture the relevant literature. For example, one excluded paper explored a mix of trauma-informed practices and trauma-specific interventions, though the focus appeared to be on the latter and thus the paper was not deemed eligible to be included in this review (Truesdale et al., 2019). Similarly, there is likely to be literature exploring lone principles associated with TIC, such as promoting 'choice' in IDD settings as one of the key facets of TIC (Rajaraman et al., 2022, 2023). However, such papers were considered not to reflect the full system-focussed all-encompassing TIC approach and thus were excluded. The full-text phase of screening regrettably lacked inter-rater reliability checks, which would have been beneficial given the number of papers where eligibility was deemed ambiguous by the main researcher. However, these papers were discussed in depth with the research supervisor which helped to strengthen this phase of eligibility screening. Also, the search terms may have filtered out potentially valuable papers because they did not explicitly identify TIC or IDD in their title or abstract. Lastly, this review only included English language studies and thus the geographical and cultural diversity of papers is likely to be limited. Moreover, most of the included papers in this review were from either America or the UK, and there are likely various distinctive organisational and system level factors that would limit the transferability to other systems of care in different countries.

Conclusion

Overall, the key findings from this scoping review suggest that there are opportunities for TIC to be embedded within IDD organisations and there are emerging accounts of incorporating TIC principles into specific IDD service models. Findings highlighted the importance of considering and implementing TIC across micro, meso and macro levels, though there were challenges and barriers to doing so at each of these levels. Moreover, most of the existing literature consists of documented uses of TIC and rigorous evaluation of TIC implementation to establish effectiveness has lagged. The most recent advancement in the research was the development and provisional evaluation of a TIC training programme for IDD care staff, which was an identified requisite to implementing TIC within the earlier literature. Notably, recommendations for future research include exploring the experiences of and perspectives on TIC from individuals with IDD themselves and their families. Moreover, there is need for ongoing empirical research to explore how best to implement TIC using clear, quantifiable, and comparable methodology, including longitudinal research investigating the implementation of TIC organisational culture on outcomes across IDD services, for service providers and recipients alike. Though ultimately, the existing literature poses that the essence of TIC, that is an attentiveness to trauma and commitment to prevent further harm in the lives of all people, has considerable potential to address an array of pervasive challenges within the IDD field, allowing both those receiving and providing services to thrive.

Key messages and implications:

1. There are opportunities for embedding TIC within IDD contexts, though further research is required to explore the implementation of TIC using clear, consistent, and comparable measures of TIC and associated outcomes within IDD organisations.
2. There is emerging practice-based evidence suggesting TIC training for staff may enhance understanding of trauma and promote TIC practices. Though, there is a lack of empirical investigation exploring the impact of TIC for individuals with IDD and their support networks.
3. There is emerging evidence for practice suggesting that TIC organisational culture benefits staff satisfaction and wellbeing. However, there is a lack of understanding about the long-term implications of TIC and further longitudinal research exploring the impact of TIC for both staff and clients is required.
4. There is a growing body of literature regarding challenges and barriers to implementing TIC in IDD organisations, including lack of TIC training and knowledge among staff and high staff turnover. Further research is required to develop validated tools to assess gaps in TIC practices and identify related barriers to implementation.

Paper 3: Integration, Impact, and Dissemination Plan

The aim of this paper is to provide an overall reflective and critical account of the research processes. The integration of the empirical study and scoping review will be explored, along with the potential impact of the research and plans to disseminate the findings.

Integration

Areas of Concordance and Discordance

The empirical study and scoping review are closely interlinked, with the PTMF considered to dovetail with TIC (Hamer et al., 2022). In fact, the first core question of the PTMF, ‘what has happened to you?’, is the widely referenced slogan of TIC, with both aiming to move away from a biomedical frame of ‘what is wrong with you?’ (Johnstone & Boyle, 2018). Broadly, the PTMF and TIC share the aim of promoting healing, recovery, and empowerment among individuals who have experienced psychosocial adversity. They both emphasise the importance of considering the impact of adversity and trauma on an individuals’ life, such as the way it can shape their ways of relating, thinking, feeling, and behaving. The slight difference between the two frameworks is perhaps the broader perspective on the sources of adversity and distress posited by the PTMF, which encourages critical examination of systemic power imbalances and social inequalities that contribute to psychological distress (Boyle, 2022). Whereas TIC focuses more narrowly on the effects of individual traumatic life experiences. Thus, the PTMF emphasises more broadly how powerlessness can be threatening for people and may explain people’s experiences of emotional distress, unusual experiences, or troubling behaviour (Cromby, 2022). Though generally the PTMF is often considered a trauma-informed approach and TIC practices within services are compatible with much of the framework (Johnstone et al., 2019).

This thesis speaks to the concordance between the PTMF and TIC as they relate to thinking about and working with people diagnosed with learning disabilities and/or developmental disabilities. The findings of both papers suggest that the PTMF and TIC both offer significant ideological shifts in the way we think about, understand, and approach supporting individuals to promote well-being and prevent (re)traumatisation. Though interestingly, both papers acknowledged the alignment between the approaches with existing philosophies, such as the social model of disability and person-centred care. These findings suggested that there are opportunities for the PTMF and TIC to be implemented within services due to overlap with influential ideas regarding working with people with learning disabilities. However, similarly the findings of both papers highlight various challenges and barriers to implementing the approaches due to necessary culture shifts and lack of resource. This is a rather contradictory finding and would benefit from further exploration, for example comparing routinely applied principles in practice with conceptual principles within guidelines and policies.

The findings of both the empirical study and scoping review suggest that the PTMF and TIC are best considered system-wide approaches that should be applied at various levels, from individual health and social care settings to broader policy and societal structures. For example, the empirical study suggested that the PTMF could be used as a conceptual framework to think about how powers operate at different levels and pervasively impact on everyone within a system. Similarly, the findings of the scoping review suggested that much of the TIC literature in IDD settings has proposed that TIC should be considered and implemented across the micro, meso and macro level. Ultimately, this thesis has highlighted a dearth of research examining the PTMF and TIC as they relate to working with people with learning disabilities and/or developmental disabilities. This is likely due to the novelty of both approaches, though TIC research for people with IDD has lagged considerably compared to other populations (Keesler, 2014). A next step indicated by the findings of this thesis in terms of combining the approaches may be to explore whether the PTMF could be used as a specific framework to support the implementation of TIC in learning disability services across different levels of organisations.

Use of Terminology

The language used to refer to people who are diagnosed with ‘learning disabilities’ and/or ‘developmental disabilities’ is an ongoing subject of intense and essential debate. Throughout this thesis it was hoped that the language used was respectful to people who may describe themselves or be described by others using these diagnostic terms. Notably, diagnostic labels and terminology have changed over the last two centuries, with historic terms such a ‘mentally handicapped’ deemed offensive and de-humanising. The language used has been shown to have powerful and profound negative impacts on the quality of care and outcomes for people (Crocker & Smith, 2019). Thus, such terms have largely been replaced by more neutral and person-centred language such as ‘person with a learning disability’. However, within communities of people with learning disabilities and/or developmental disabilities, such as autism, there is ongoing debate regarding language. Some individuals advocate for identity-first language, which places the disability before the person (e.g., ‘autistic person’) to acknowledge and embrace the disability as part of the person’s identity (Botha et al., 2023; Bury et al., 2023). Conversely, proponents of person-first language (e.g., ‘person with autism’) argue that it is important to emphasise the person rather than the disability, which may help reduce stigma (Holland, 2011). Ultimately, both aim to recognise the challenges faced and support required, without portraying the diagnosis as a problem to be fixed (Dunn & Andrews, 2015).

In addition, the language used to term associated ‘mental health disorders’ and ‘challenging behaviour’ is also widely contested. The PTMF hopes to provide an alternative to psychiatric diagnostic labels such as ‘schizophrenic’ and more broadly the use of ‘disorders’, which can be stigmatising and induce a sense of otherness (Kinderman et al., 2013). Instead, the PTMF encourages the use of terms such as ‘emotional distress’ or ‘troubling behaviour’ (Johnstone & Boyle, 2018). Using more neutral and humanistic language may be particularly empowering for people with learning disabilities and/or developmental disabilities considering individuals often experience intersectionality of stigma with regard to (dis)ability, as well as emotional and behavioural distress (Spassiani et al., 2017).

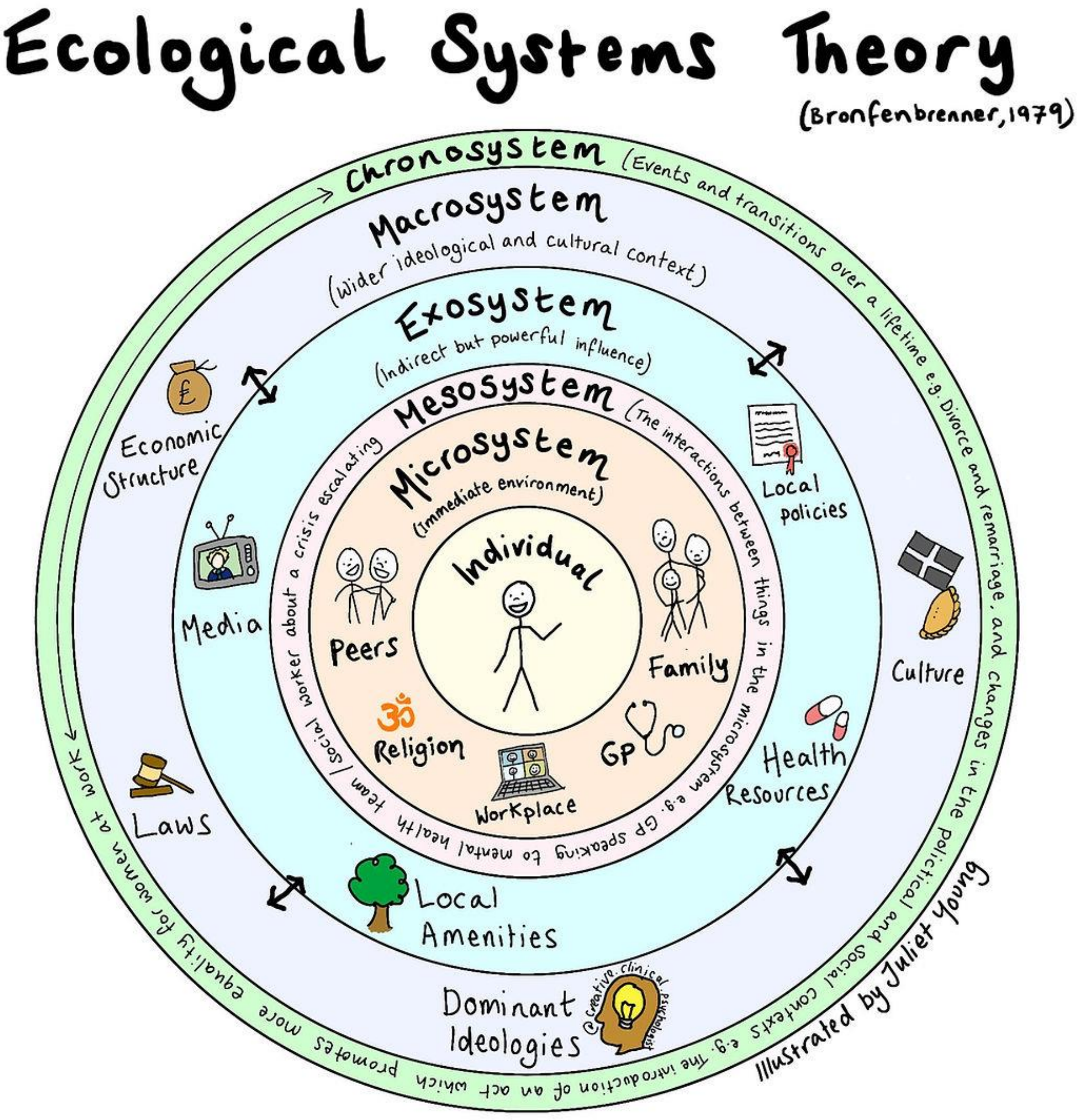
Such debates highlight that there is no one-size-fits-all resolution, and each person will likely have their own unique perspectives and preferences which should ultimately be respected (Andrews et al., 2022). For the purposes of this research, person-first language was chosen over identity-first language regarding (dis)ability due to the focus on people with a diagnosis of a learning disability. The acronym ‘IDD’ was used within the scoping review for consistency with language used in the literature. The term ‘psychological distress’ was chosen in this paper to reflect the spectrum of thoughts, feelings, and behaviours that people experience as distressing. However, I acknowledge these choices would not be the preference for many people, and thus could cause offense and inadvertently accentuate stigma (Gernsbacher, 2017). I can only apologise to people whom this is the case.

Impact

The empirical study and scoping review are both the first of their kind and offer novel contributions to the applied and academic field of clinical psychology. Considering the aforesaid ideological shifts proposed by the PTMF and TIC, the approaches have potential to significantly transform the way we understand and approach psychosocial adversity and related psychological distress within services for people with learning disabilities and/or developmental disabilities and more broadly within society. The potential beneficiaries of this research span from individuals diagnosed with learning disabilities and/or developmental disabilities, their families and friends, and people who work as carers to support them, to people who run community and residential services, professionals who work within health and social care learning disability services, researchers in this field, and policy makers. The related potential ‘real-world’ applications are helpfully mapped from an ecological perspective using Bronfenbrenner's (1979, 1992) ecological systems theory. As depicted in Figure 3, the four-level circular diagram represents the complex interwoven systems that directly and indirectly impact on an individual. Using an ecological lens to consider the impact of this research aligns with the social and contextual models of disability underpinning the research, and maximises significance and reach of the findings (Penfield et al., 2014).

Figure 3

Bronfenbrenner's (1992) Ecological Systems Theory (Illustration by Young, 2021)



Microsystem

The findings of this research have highlighted potential direct impact at the micro level for individuals within their everyday lives. Both papers proposed that direct support, in the form of daily support by care staff or targeted interventions by various professionals, could benefit from using trauma-informed approaches and considering PTMF ideas, such as how power is operating in the person's life and microsystem. The potential beneficial impact for individuals themselves included promoting choice and self-determination, the reduction of over-medication and restrictive practices, and safer and more compassionate interactions with support services. People who meet with services utilising PTMF and TIC practices, thus centring disempowerment and adversity, are potentially more likely to be understood holistically and receive support that tends to their trauma-related needs. Likewise, potential impact for individuals who work as carers include receiving formal trainings or consultation from a PTMF or TIC approach to feel more empowered and rewarded in their jobs. In addition, TIC and the PTMF could impact on fostering more supportive working environments by holding in mind the experiences of staff members as well as clients. The findings ultimately suggest that if trauma-informed principles are not endorsed, it is likely that some individuals will be unable to engage with services leading to escalations of distress (Roy et al., 2020). Moreover, crises related to compassion fatigue and burnout that directly impact care staff will likely persist (Robey et al., 2021).

This thesis highlighted relational trauma and disempowerment as specific negative operations of power that individuals experience at the micro level, particularly in relation to their care staff. To maximise the impact of such findings, the role of the PTMF and TIC in advocating for and intervening from a position of interpersonal safety should be highlighted as having potential to improve relational experiences for individuals. This is important considering the ongoing serious incidences of systemic abuse individuals face (Bubb,2014). In addition, the PTMF has been used in adult mental health peer-support contexts (A. Griffiths, 2019), and it will be important to explore the potential impact of peer-support models using the PTMF for this population. To maximise the impact of these preliminary findings at the micro level, future enquiry into the PTMF and TIC should meaningfully collaborate with individuals impacted at this level to truly embody trauma-informed values of collaboration and empowerment within research (K. E. Jones et al., 2020).

Mesosystem

At the meso level, this thesis has emphasised that the PTMF and TIC are particularly relevant to people with learning disabilities as they are disproportionately disempowered. The focus on power imbalances and empowerment among the findings of this research has the potential to address well-documented ‘power over’ relationships in health and social care settings. That is, the PTMF and TIC offer frameworks that consider power and may positively impact empowerment by questioning and addressing the degree of control and authority professionals and organisations hold over people. The PTMF explicitly considers related negative operations of power such as coercion, communication differences, and legal frameworks around decision-making in hopes to address and reduce such power imbalances. Thus, it is hoped the findings of this research, in terms of the applicability of the PTMF to learning disability services, will contribute to the shift of power within services to empower people with learning disabilities (Whaley, 2019). Moreover, the principles of the PTMF and TIC appear to align with the focus on social inclusion and empowerment within self-advocacy groups (Anderson & Bigby, 2017). Thus, it will be important to consider how the findings of this research fit with and could positively impact the self-advocacy movement, which challenges the social barriers that prevent individuals from fully participating in society (Clarke et al., 2015).

Exosystem

At the indirect yet powerfully influential exo level, policies impact the availability and accessibility of resources, opportunities, and support services that people need to thrive. There are several key policies aimed at improving the care and support provided for people with a diagnosis of a learning disability and/or developmental disorders. The findings of this research could be impactful in influencing fulfilment and further development of such policies. For example, this research largely aligns with the initiatives of the ‘Valuing People’ (DoH, 2001) and ‘Valuing People Now’ (DoH, 2009) social policies to empower and support people with learning disabilities to live ordinary lives. Though, the findings of this thesis would suggest that despite the publication of these policies over 20 years ago they have not been fulfilled, which fits with surveys that suggest progress has stalled (Paradigm, 2017). The alignment between the ideological concepts of TIC and the PTMF with these policies may suggest that they could be used to ensure the goals outlined are not forgotten and can be meaningfully reached. Similarly, the potential impact of implementing TIC and the PTMF could support the implementation of the top three 'Transforming Care' priorities, to offer people choice and control, person-centred care, and a good and meaningful everyday life (DoH, 2012).

Both the PTMF and TIC align with many of the NHS policy initiatives for this population, such as 'Building the Right Support' (NHS, 2015). Arguably the findings of this thesis advocate that a culture shift in services is needed to ensure services are providing trauma-informed, compassionate, and empowering care outlined in such policies. Moreover, the findings of the empirical study highlighted that professionals' experience challenges advocating and practicing in line with these policies within services as other models can impede working in this way. Further impact could be achieved if the PTMF and TIC were incorporated into good practice guidelines for professionals working in learning disability services. At the meta level, the PTMF could be used to recognise and reflect on the impact and power of choices made in the various clinical and research agendas and policies that may neglect certain ideologies and groups of people (Ne'eman & Bascom, 2020).

Macrosystem

The findings of this research highlight that the PTMF and TIC are intended to be impactful at the macro level, largely viewing trauma and resultant psychological distress as a social, cultural, and political issue. That is, they aim to challenge broader social and culture norms and policies that may be contributing to distress (Read & Harper, 2022). Indeed, the findings of this thesis could impact the wider ideological and cultural context, as for example the PTMF appears to represent a conceptual framework that could shift the discriminatory historical narratives that prevail around people with learning disabilities. The social justice orientation embodied by both approaches could be used to address stigma around dis(ability), which impacts people's sense of culture and identity (Scior et al., 2020). This would be particularly indirectly impactful on the microsystem, as it has been posited that true community inclusion can only occur when stigma is combatted (Spassiani & Friedman, 2014). Ultimately, the findings of this thesis suggest that the PTMF and TIC could be used within critical and community psychology to address oppressive structures at the macro level (Nelson, 2013). More broadly, this thesis hopes to acknowledge the power within systems and recognise the importance of redressing power imbalances and promoting allyship (Scholz et al., 2021).

Evidencing impact

As highlighted within both papers, the potential benefits and impact of implementing the PTMF and TIC need to be further meaningfully evidenced. Implementation science offers a model to explore the processes and strategies that ensure effective adoption and sustained use of research findings (Bauer et al., 2015). Firstly, implementation research could be used to evaluate strategies used to promote the adoption and use of TIC and the PTMF. This would involve examining the facilitators and barriers, identifying effective implementation strategies, and evaluating the impact of these on the uptake and sustainability of both approaches (Handley et al., 2016). To ensure that the PTMF and TIC are being implemented as intended, fidelity assessments could be used to evaluate whether principles and practices were being used consistently (Sanetti & Luh, 2019). Outcome evaluations could be used to measure the impact of the PTMF and TIC on outcomes across services (Stover et al., 2021), for example assessing meaningful indicators of change such as quality of life, staff and client satisfaction, and engagement with services. Finally, implementation science also speaks to the importance of dissemination efforts to promote the widespread uptake of approaches (Rapport et al., 2018). This would involve further development of training materials and providing supervision to staff and clinicians to promote awareness and understanding of the PTMF and TIC.

Potential pitfalls

Although I consider myself an advocate for the PTMF and TIC approaches, I recognise the complexity around implementing associated principles and practices, particularly within settings for people who are diagnosed with learning disabilities and/or developmental disabilities. For example, the ideological shift could be perceived as the replacement of one dogmatic approach, the biomedical model, with another related to adversity and trauma saturated explanations. That is, critics have posited that TIC and the PTMF are similarly reductionist but re-packaged ways of categorising human responses to trauma (Birnbaum, 2019; Morgan, 2023). Thus, alike the considerations regarding language, it is important that the PTMF and TIC are positioned as approaches that promote choice and enable people who seek support from services to develop their own narratives, rather than another approach that imposes a particular ideological stance.

Additionally, in attempting to do differently the PTMF and TIC face the task of promoting a culture shift and transforming care in times of extreme economic austerity. In fact, NHS services that provide care to people with learning disabilities and/or developmental disabilities are currently facing unprecedented challenges with capacity and demand (NHS, 2020). The philosophies of the PTMF and TIC, and the related importance of social context for empowerment, are undermined by the vast declines within statutory care. For example, a recent study exploring the impact of austerity on people with learning disabilities in England found the majority of people in their sample had lost care, which had detrimental impacts on their quality of life, independence and future aspirations (Forrester-Jones et al., 2021). Thus, potential challenges that may arise when implementing TIC and the PTMF include resource constraints and related resistance to change. Moreover, implementation would require significant financial investment in training and resources which may not be feasible for services. Such barriers emphasise the potential role of aforementioned peer advocacy models for implementing the PTMF in the face of austerity related declines in services (A. Power et al., 2016).

Dissemination

With increasing momentum building for both the PTMF and TIC, it is hoped that it will be possible for this research to be widely shared and easily accessible for varied audiences. The empirical study has been presented to trainee clinical psychologists at Royal Holloway University of London. The presentation focused on the disempowerment of people with learning disabilities within services and the promise offered by the PTMF used by professionals to centre power when thinking about and working with individuals in this context. Audience reflections following the presentation indicated enthusiasm for the project and posed thoughts regarding hierarchical power within services and the importance of empowering professionals at all levels to consider their work in relation to the PTMF. The full thesis will be made available via the universities open access system 'Pure'.

In addition, participants who consented to be contacted have been provided with a summary of the research. The findings of both papers will be prepared into executive summaries and distributed to psychological professionals who work within learning disability services in the UK via the BPS and DCP Faculty for People with Intellectual Disabilities emailing list, with abstracts to be published in The Bulletin of the Faculty for People with Intellectual Disabilities. A summary and link to the thesis will be shared with the PTMF research group and posted on the PTMF research section of the BPS website. To reach a broader audience of professionals who work in learning disability settings, summaries will also be shared on the UK Health and Learning Disability Network website and on Twitter and relevant professional Facebook groups. Further dissemination is planned via poster presentations at relevant conferences within the next year, such as the BPS DCP Faculty for People with Intellectual Disabilities annual conference in May 2024. In addition, it is hoped that the findings and learning from the research will be discussed with experts by experience and their families to influence future work exploring the PTMF for people with learning disabilities and promote meaningful co-production within further work in this area. This will be achieved by seeking opportunities via learning disability self-advocacy organisations and the working group for researching PTMF and people with learning disabilities.

To disseminate the findings more widely within the academic sphere and contribute to the emerging evidence base, it is intended that both papers will be prepared and submitted for publication in peer-reviewed journals. Journals relevant to the topic of the empirical study and appropriate for qualitative research will be considered, such as the Journal of Intellectual Disabilities, Advances in Mental Health and Intellectual Disabilities, and the British Journal of Learning Disabilities. For the scoping review, the Journal of Policy and Practice in Intellectual Disabilities will be approached. Reaching as wide an audience as possible is important given the relevance within and beyond clinical psychology to increase awareness of the potential applicability of the PTMF and TIC within learning disability services, and hopefully inspire further research in this area.

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Appendices

Appendix A

Example excerpts of researcher's reflective journal

<u>October 2022</u>
I've just conducted my fourth interview; I'm really enjoying this part of the process and can feel my skills as a qualitative researcher / interviewer developing with each interview. I can definitely feel a slight shift in my interview style as I become increasing familiar with the interview schedule and my confidence builds with conducting the interviews. It feels more free flowing, allowing the participant to lead the direction of the interview whilst I become more confident to hold different areas of the schedule in mind.

It's very motivating and encouraging meeting with participants as they seem really interested in the research, enthusiastic about the PTMF for PWLD, and want to hear about the results. I will need to consider how and when I share these to get their reflections on findings. It's interesting that within most conversations at the end of interviews, participants express a desire to be put in touch with other professionals drawing on the PTMF in LD services. I get an overwhelming sense that it is quite isolating and lonely drawing on the PTMF in this context. I hope I can think about this further when considering the impact and dissemination of my findings, perhaps exploring whether participants want to consent to sharing their contact details with each other…

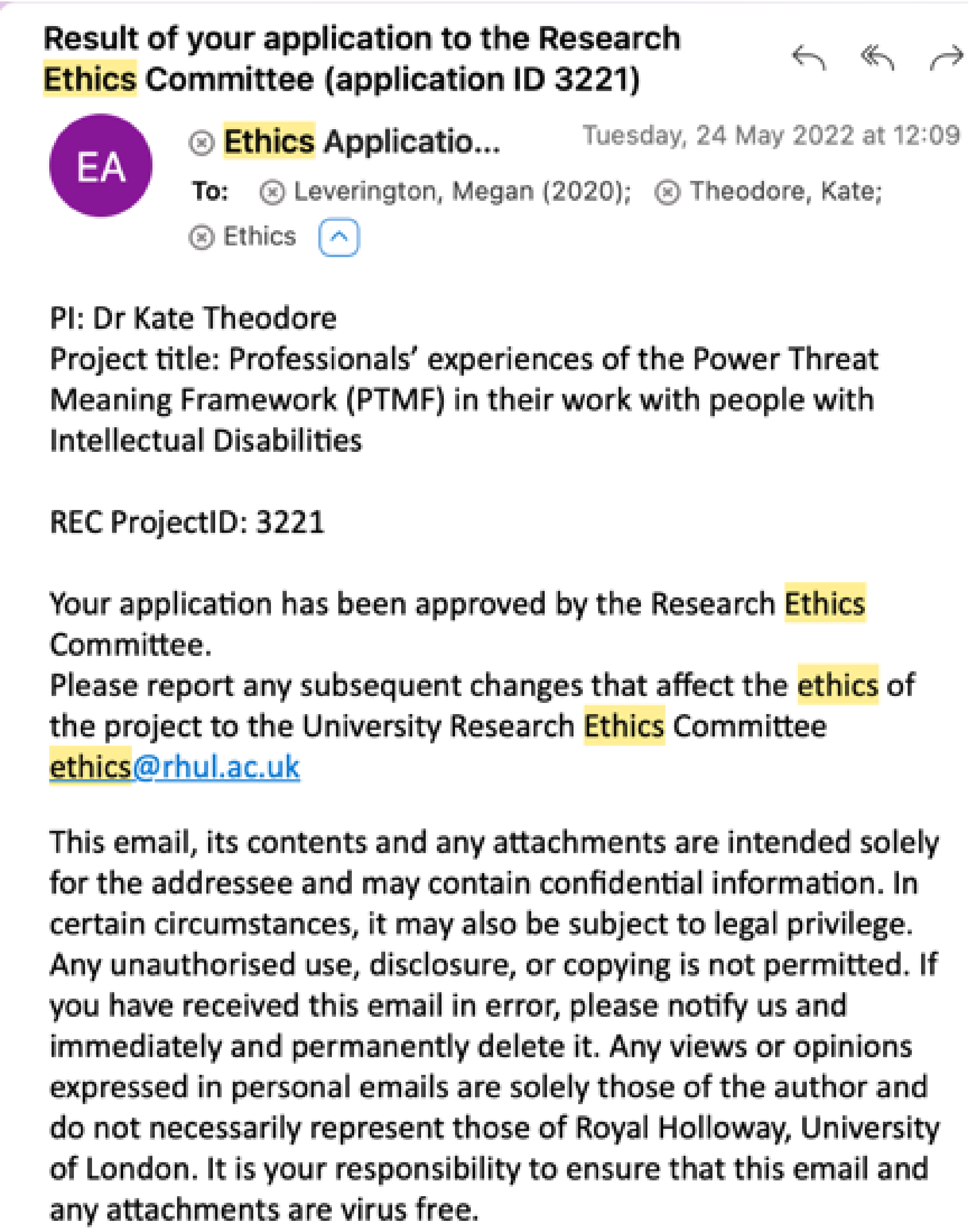
<u>January 2023</u>
I've just started my first round of coding and I'm noticing that I am coding everything in fear that I might miss something, or that it may later transpire to be relevant. I'm wondering if I need to be more focused on keeping the research questions in mind when coding so that only code what can be relevant, but then aware I am biasing this – to discuss with Kate in research supervision later today.

It was really useful to discuss my coding so far with Kate for re-assurance and tips as I am a novice (qualitative) researcher! Kate helpfully recommended to broaden out my quotes so that when I transfer to Nvivo there is more context. Hearing Kate's reflections on the interview and my codes was helpful to broaden perspectives and self-reflexivity around what I may be paying more or less attention to in my coding. I'm going to hold this in mind when coding the remaining transcripts and take anything I think is complex / nuanced / back to research supervision.

<u>March 2023</u>
I've made the decision to move from coding into phase 3 of my analysis - it's finally time to start the interpreting patterns of meaning and generating initial themes! Having so many (669!) codes to contend with certainly feels overwhelming, but strangely containing as I feel confident that I am ready to move on from coding and have rigorously attended to each piece of data in a systematic way. I can sense that I feel a pressure to capture all the rich meanings that I've interpreted (and could be interpreted further!) but have just read in the Braun and Clarke textbook the suggestion of very few themes (3-7 including subthemes) in an 8,000-word report… so I'm really trying to prepare myself to be accepting that there are multiple rich analytic stories around the dataset, and I only have opportunity to tell one very specific and concise narrative from my subjective interpretations. Some initial salient and consistent patterns of meaning appear to be around a focus on the power part of the PTMF for PWLD in relation to enhancing existing models, like PBS. But also, the focus on power / PTMF feeling more relevant systemically and at a system-wide level. I'm interested in these ideas in relation to my research questions and how they relate to both participants perspectives and experiences, but also some of the opportunities and challenges of drawing on PTMF in LD contexts.

Appendix B

Royal Holloway University of London Research Ethics Committee approval



Result of your application to the Research Ethics Committee (application ID 3221)

Ethics Applicatio... Tuesday, 24 May 2022 at 12:09

To: Leverington, Megan (2020); Theodore, Kate; Ethics

PI: Dr Kate Theodore
Project title: Professionals' experiences of the Power Threat Meaning Framework (PTMF) in their work with people with Intellectual Disabilities

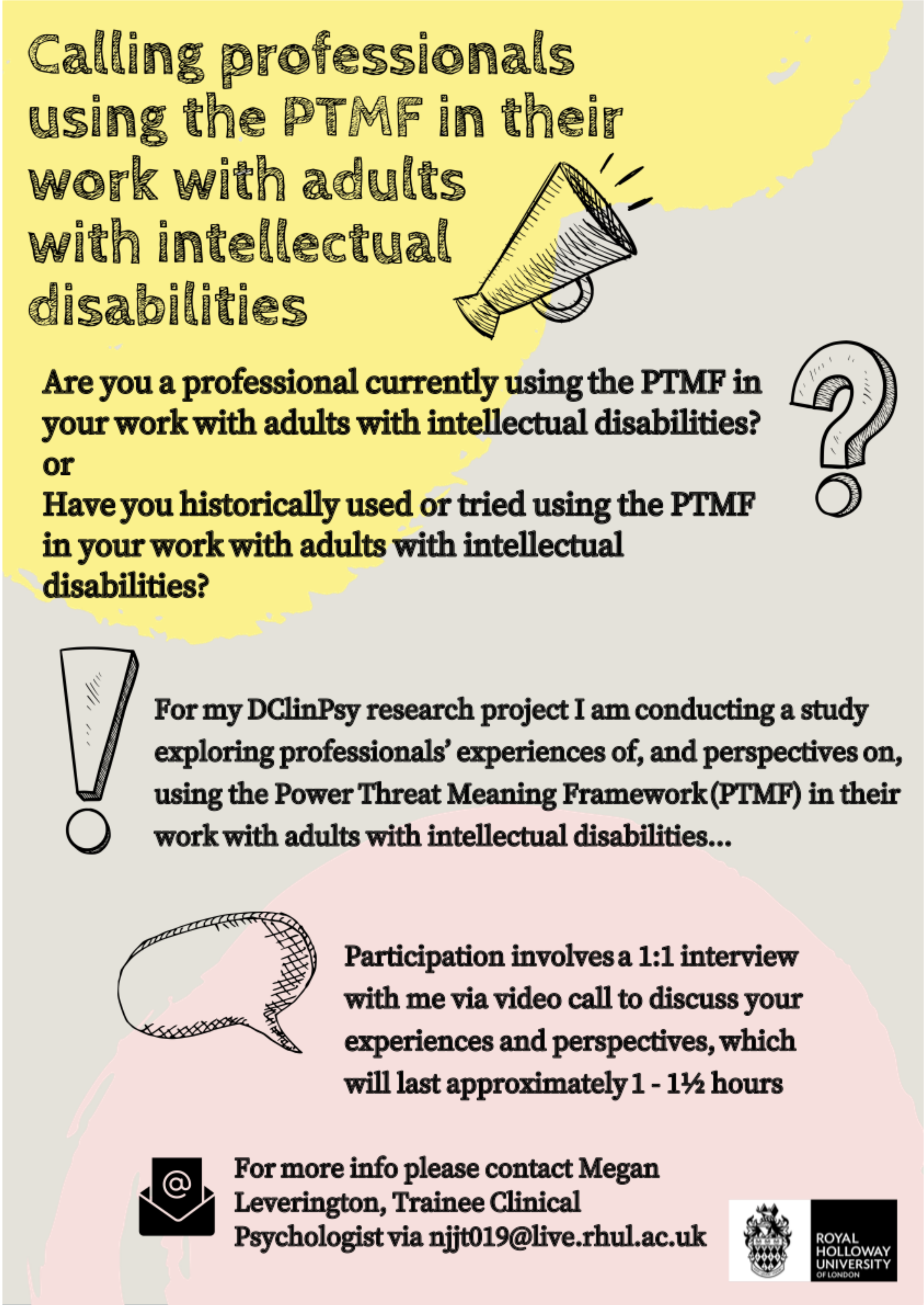
REC ProjectID: 3221

Your application has been approved by the Research Ethics Committee.
Please report any subsequent changes that affect the ethics of the project to the University Research Ethics Committee ethics@rhul.ac.uk

This email, its contents and any attachments are intended solely for the addressee and may contain confidential information. In certain circumstances, it may also be subject to legal privilege. Any unauthorised use, disclosure, or copying is not permitted. If you have received this email in error, please notify us and immediately and permanently delete it. Any views or opinions expressed in personal emails are solely those of the author and do not necessarily represent those of Royal Holloway, University of London. It is your responsibility to ensure that this email and any attachments are virus free.

Appendix C

Recruitment poster



Calling professionals using the PTMF in their work with adults with intellectual disabilities

Are you a professional currently using the PTMF in your work with adults with intellectual disabilities?

or

Have you historically used or tried using the PTMF in your work with adults with intellectual disabilities?

For my DClinPsy research project I am conducting a study exploring professionals' experiences of, and perspectives on, using the Power Threat Meaning Framework (PTMF) in their work with adults with intellectual disabilities...

Participation involves a 1:1 interview with me via video call to discuss your experiences and perspectives, which will last approximately 1 - 1½ hours

For more info please contact Megan Leverington, Trainee Clinical Psychologist via njjt019@live.rhul.ac.uk

ROYAL HOLLOWAY UNIVERSITY OF LONDON

Appendix D

Eligibility screening questionnaire

PTMF ID Project – Participant Eligibility Screening Call Protocol

Minimum 'cut-off' for professionals eligible to take part (subject to discussion with research supervisor if unclear);

1. Must be currently using or have historically used PTMF ideas to inform clinical practice in at least one clear area of work with people with ID (direct with clients, indirectly with MDT or staff teams, within supervision, organisations, consultation etc.)

   And;
2. Must be able to identify at least 4 of the 6 main PTMF guided discussion questions

   And either;

   a) Attended a training or presentation related to the PTMF

   Or,

   b) Read at least one of the PTMF documents

"Thank you for expressing interest in participating in this study and for taking the time to talk with me today.

1. To confirm you are eligible to take part in this study, please confirm that you:
   a) Are a health professional working in intellectual/learning disabilities services for adults
   b) Have used the PTMF in my work with people with intellectual/learning disabilities (recently or historically)

"*I would like to now ask you some brief questions about your knowledge and experience of using the PTMF in your work. This is not a test, these questions are being asked to check participants have awareness of some of the key concepts of the PTMF, but please do not worry about getting all responses correct. Please discuss and answer these questions honestly. You will not be screened out if you express positive or negative views about the PTMF. The questions are being asked to check familiarity with key concepts and will be used to inform decisions about who to interview if more people volunteer than can take part."*

2. What areas of your work have you used PTMF ideas to inform clinical practice? (e.g., direct with clients with intellectual disabilities, indirectly with MDT,staff teams or carers, within supervision, organisations, consultation etc.)

3. Are you able to identify the 6 main questions the PTMF offers for developing narratives (please put down all you can remember, and do not worry about getting the wording correct, or if you cannot remember all questions):

4. Have you attended any training or presentations related to the PTMF? If so, what/where?

5. Have you read any of the PTMF documents? If so, which? (e.g., The BPS/DCP PTMF main/full policy document (414 pages) or overview (139 pages), guided discussion, PTMF formulation template, short summary of principles and aims of PTMF etc.)

"Thank you for speaking with me today and for expressing interest in this study. It sounds like your experience and knowledge around PTMF/intellectual disabilities you have shared with me today will be a good match with the research questions of this study and therefore you are eligible to take part if you would still like to. Would we be able to arrange a time for the interview session now? I will confirm this time via email, with a short demographic questionnaire attached for you to return to me at your earliest convenience. This questionnaire helps us to understand who takes part in the study and is important when considering the findings.

If deemed NOT eligible: "Thank you for speaking with me today and for expressing interest in this study. Unfortunately, it would appear that this study may not be a good match with your knowledge and experience, in terms of the specific interview questions that would be asked. Though I really appreciate your time today and it was good speaking with you."

Appendix E

Semi-structured interview schedule

Semi-Structured Interview Schedule

Professionals' experiences of the Power Threat Meaning Framework in their work with people with Intellectual Disabilities.

"Thank you for volunteering to participate in this study, which aims to explore professionals experiences and perspectives on the PTMF in their work with people with intellectual disabilities. Today, I'm going to be asking some questions about your experiences and thoughts about the PTMF and your work with people with ID, this should take around 1-1.5 hours. You have received the information sheet and consent form which you have kindly returned, thank you for this, did you have any questions before we get started?

Just to note that if there are any questions you don't wish to answer, that's absolutely fine please just let me know. At times I may ask follow-up questions or use prompts to gather more information about specific topics."

Theoretical Background:

1. What is your understanding of the main principles of the PTMF? Can you describe to me your sense of what the PTMF is?

2. In what ways do you think the framework is relevant to the lives and experiences of adults with ID?
    a. *Power – what do you see as the main power imbalances that people with ID experience in their lives? (e.g., societal attitudes, poverty, lack of ordinary opportunity, lack of ability to influence?)*
    b. *Threat – what threats do you see people with ID commonly experiencing? (e.g., physical abuse, sexual abuse, emotional abuse, loss/lack of relationships, unstable homes, lack of opportunity?)*
    c. *Meanings – what do these threats mean to people with ID? (e.g., poor self-esteem, stigma, shame, anxiety, anger, devalued social role?)*
    d. *Threat responses – what emotions and behaviour do you see which be understood as responses to these threats?*

3. In what ways do you think the framework is more/less relevant to adults with ID compared to other client groups?

   a. *Do you think the framework adds anything to existing ways of thinking about the lives of people with ID? If yes, what aspects/how does it do this? If no, what is the framework comparable to?*
   b. *Do you feel there is anything missing / aspects that are not covered by the framework that you think are particularly relevant to the lives of adults with ID?*

<u>Implementation: Opportunities and Barriers</u>

4. What initially drew you to use the framework in your work with adults with ID? Did you have hopes for your clients, yourself, or the organization?
   a. *Did you introduce it or was it already used?*
   b. *What was the existing setting / culture like?*
   c. *How is the framework similar / different to what's been used before?*
   d. *Had you used the framework with populations other than adults with ID?*

5. In what ways have you used ideas from the framework in your work with adults with ID? Please be as specific as you can with case examples whilst obviously protecting the anonymity and confidentiality of your clients
   a. *Which ideas from the framework have you used? (e.g., guided discussion, patterns, core questions?)*
   b. *How have you used the ideas with service users, systems, teams, organizations and/or in other ways?*
   c. *If not mentioned provisional patterns, enquire about familiarity and use of these*
   d. *If not mentioned either direct, indirect and organisation level, enquire about these*

6. How have you found implementing PTMF ideas in your work with adults with ID and in services for people with ID?
   a. *How confident do you feel using the framework in your work with adults with ID?*
   b. *Are there aspects that have been easier / harder to implement?*
   c. *What gets in the way of using ideas from the framework in your work with adults with ID? Have you experienced challenges implementing the framework? If so, what?*
   d. *Are there differing views in the team? If so, how do you navigate this?*
   e. *Has there been any resistance from other colleagues?*

7. In what ways do you think you could use and/or want to use ideas from the framework in your work with adults with ID?
   a. *What ideas do you have for using the PTMF with service users, systems, teams, organizations and/or in other ways?*

Evaluation: Strengths and Weaknesses

8. What do you think the strengths of the framework are from your experiences using it in your work with adults with ID?
    a. *Are there specific elements or ideas that have been particularly helpful in areas of your work?*
    b. *Have there been strengths in engagement, communicating ideas, meeting clients' goals?*
    c. *Has there been any positive impact on service users, staff, or the wider system? On team culture or team functioning? On how staff think about service users? If yes, how do you know? Evidence of this? How have you evaluated your work?*
    d. *Are there strengths of the framework compared to other models you have used in the past or are still using?*

9. What do you think the weaknesses of the framework are from your experiences using it in your work with adults with ID?
    a. *Are there specific elements or ideas that have not been helpful/been least helpful in your work?*
    b. *Have you experienced any difficulties when using the framework in your work?*
    c. *Have you experienced any difficulties engaging service users or staff with the PTMF?*
    d. *Have you experienced any difficulties communicating with service users or staff about the framework?*
    e. *Have you experienced challenges relating to the wider system and existing ways of working?*
    f. *Are there weaknesses of the framework compared to other models you have used in the past or are still using?*
    g. *How have you navigated these challenges and what's been helpful in overcoming them?*
    h. *What do you feel would need to change in order overcome or manage these challenges?*
    i. *Have these challenges had an impact on you?*

Future Directions

10. Do you think the PTMF should be used more routinely in ID services, and if so, what would be needed to enable that to happen? If not, or you are not sure, why not?
    a. *Do you have any plans to take this forward?*
    b. *Do you have any ideas for research that would be helpful for implementing the PTMF clinically?*

11. Do you have any ideas about specific adaptations of the PTMF that could make it more relevant and/or useful for working with adults with ID?
    a. *Are there any types of resources that you think would be helpful for implementing the PTMF clinically?*

12. Is there anything you wanted to speak about that you haven't had the chance to mention in relation to the PTMF and your work with adults with ID?

Note to self: at the end of the interview thank participants and outline what happens next, check if participant had consented to be contacted for summary of findings etc. Did anything come up in the interview to take a note of/require any follow up (e.g., safeguarding concerns)?

Appendix F

Participant information sheet

Prospective Research Participant Information Sheet

Department of Psychology

Royal Holloway, University of London

Project Title: ***Professionals' experiences of the Power Threat Meaning Framework (PTMF) in their work with people with Intellectual Disabilities (ID)***

Primary Researcher: ***Megan Leverington*** *(Megan.Leverington.2020@live.rhul.ac.uk)*

Supervisor: ***Dr Kate Theodore*** *(Kate.Theodore@rhul.ac.uk)*

Introductory paragraph

You are being invited to take part in a research project. Before you decide to consent to take part it is important for you to understand why the research is taking place and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us if there is anything that is not clear or if you would like more information. Please consider carefully whether you wish to consent to take part.

Why is this research being conducted?

My name is Megan Leverington, and I am a Trainee Clinical Psychologist at Royal Holloway, University of London. For my doctoral thesis, I am conducting a research project exploring professionals' experiences of, and perspectives on, using the Power Threat Meaning Framework (PTMF) in their work with people with intellectual disabilities (ID). This will be the first known study exploring the PTMF specifically in the context of working with people with ID and their systems. The project hopes to understand:

1. The clinical applications of the PTMF for people with ID and their systems
2. The strengths and weaknesses of the PTMF for this population

Clinical applications of the PTMF for people with ID may include for example, but is not limited to, direct work with clients and families, indirect work with staff teams and/or within services and organisations. The study therefore hopes to provide an understanding of how professionals are using the PTMF in their work with people with ID and their systems, and what the barriers to using the PTMF might be. The study will hopefully also inform future developments and adaptations of the PTMF specifically for people with ID and their systems.

Why have I been invited to take part?

You have been invited to take part because you are **a professional working in the UK with adults with ID** and **you know about the PTMF**. You have shown interest in the study because you have experiences of, and/or perspectives on, using the PTMF as it applies to working with adults with ID. Specifically, you are either

a) currently using the PTMF in your work with adults with ID, or

b) have historically used or tried using the PTMF in your work with adults with ID but do not use it currently.

I am interested in hearing about your unique professional experiences and perspectives whether they are neutral, positive, and/or negative. It is hoped that around 12-15 professionals will take part in the study to gain a broad range of experiences and perspectives.

To take part in the study, you must be either **currently working in a relevant professional role** supporting the health and wellbeing of adults with intellectual disabilities or were **within the last 6 months.** It is important that participants feel **sufficiently familiar with the PTMF in their work.** To check this together, there will be an **initial brief (approx. 10 minutes) eligibility screening call** simply to ensure you are familiar enough and confident that you have adequate experiences of and perspectives on using the PTMF in your work to answer the study questions in ample detail.

Do I have to take part?

No. It is up to you to decide whether you wish to take part or not. You can withdraw from the study at any time, without any consequences and without needing to give a reason, and you can withdraw your data until **31st** ***January 2023*** by contacting the primary researcher. If you decide that you wish to withdraw your data from the project, the researcher will remove your data from the analysis. After this date the data will be included in analysis and the research will be submitted as a thesis for assessment and withdrawing your data will no longer be possible.

What will my participation involve?

If you decide to take part and meet eligibility criteria, I will invite you to a virtual meeting at a time that suits you via **MS Teams/Zoom** (dependent on your preference). This will be a **one-off meeting** and is expected to last between **one to one and a half hours.** I will ask you semi-structured questions about your experiences of using the PTMF in your work with people with intellectual disabilities and their systems, and how you think the PTMF could potentially be used from your experience working with people with intellectual disabilities. I will also ask you about the strengths and weaknesses of the PTMF as it applies to working with people with intellectual disabilities.

With your consent, I will **audio record the meeting** so that I have an accurate record of our conversation for my analysis.

What are the possible disadvantages and risks in taking part, and how might these be mitigated?

There are no foreseeable discomforts, disadvantages or risks from taking part in this project. However, it is important to note that it is extremely rare, if not impossible, that research data can be completely anonymised. To mitigate any risks related to identifiable information, in the study, your data will be anonymised by a unique participant number. Your consent form will be stored separately from the anonymous information you provide for the research project. Your information will be kept completely confidential and stored following strict GDPR guidance.

Although there are protocols to safeguard your data, it should be acknowledged that there is always the potential that this may be circumvented.

Are there any benefits in taking part?

While there are no immediate benefits for participating in the project, it is hoped that this research will provide fellow professionals with understanding around the applications of the PTMF for people with intellectual disabilities. This could be helpful for clinical practice and lead to future developments and adaptations of the PTMF specifically for people with intellectual disabilities.

Payments

There will be no payment for taking part in this study.

What information about me will be collected and why is the collection of this information relevant for achieving the research objectives?

Demographic data (age, gender, ethnicity, profession, level of education, current professional role, current service type and years of experience working with people with intellectual disabilities) will be collected from you to be able to clearly describe the sample of participants who take part in the study. This is important to consider when thinking about and reporting the findings of the study. Of note, ethnicity is considered GDPR special category data. Any data that could be potentially identifiable will be screened for and removed from all research outputs of the study.

Identifiable data (including personal contact information and audio recordings of the interviews) will be stored within Dropbox for Business until the anticipated project end date of September 2023. This data will then be destroyed. Other research data (anonymised transcripts, demographic information, consent forms will be **stored in a repository for up to 10 years** after publication or public release of the work of the research.

Only myself as the primary researcher and my supervisor as the principal investigator will have access to the research data.

How will the results of my participation be used? Will the research be published? Could I be identified from any publications or other research outputs?

I would like your permission to use direct quotations, but anonymously without identifying you, in any research outputs as this is central to my analysis method (reflexive thematic analysis). This means you should not be able to be identified from any research outputs.

This research will be used to produce a DClinPsy thesis which will be deposited in Pure, Royal Holloway's research information system, and with the British Library to be made available via the EThOS electronic thesis service. The findings from the research may also be written up further, for example in academic publications or conference presentations.

A summary of the study findings will be made available to all participants at the end of the study. If appropriate, an easy read lay summary of the results will be produced. If you wish to receive a copy of these, you can provide your consent to be contacted on the study consent form.

Who do I contact if I have a concern about the research or I wish to complain?

If you have a concern about any aspect of this study, please contact either the primary researcher, *Megan Leverington*, *via* *Megan.Leverington.2020@live.rhul.ac.uk*, the research supervisor *Dr Kate Theodore* *via*

Kate.Theodore@rhul.ac.uk, or Royal Holloway's Research Ethics Committee via ethics@rhul.ac.uk. If you wish to make a formal complaint, please email integrity@rhul.ac.uk.

Ethical Approval

This study has received ethics approval from Royal Holloway, University of London's Research Ethics Committee, with the approval ID of REC Project ID 3221.

Safeguarding and when confidentiality may need to be breached

As professionals we have a duty of care to identify and report poor clinical practice, it has been considered that in the rare instance that poor practice was disclosed or highlighted in the study, it will need to be followed up with relevant safeguarding protocols. In these instances, confidentiality may need to be breached and concerns will be discussed with the research supervisor and other relevant parties.

Data protection

This research commits to abide by the Data Protection Act (2018). For detailed information about what this means for research participants, please visit the Research Participant Privacy Notice: *https://intranet.royalholloway.ac.uk/research/documents/researchpdf/new-intranets/research-participant-privacy-notice.pdf*

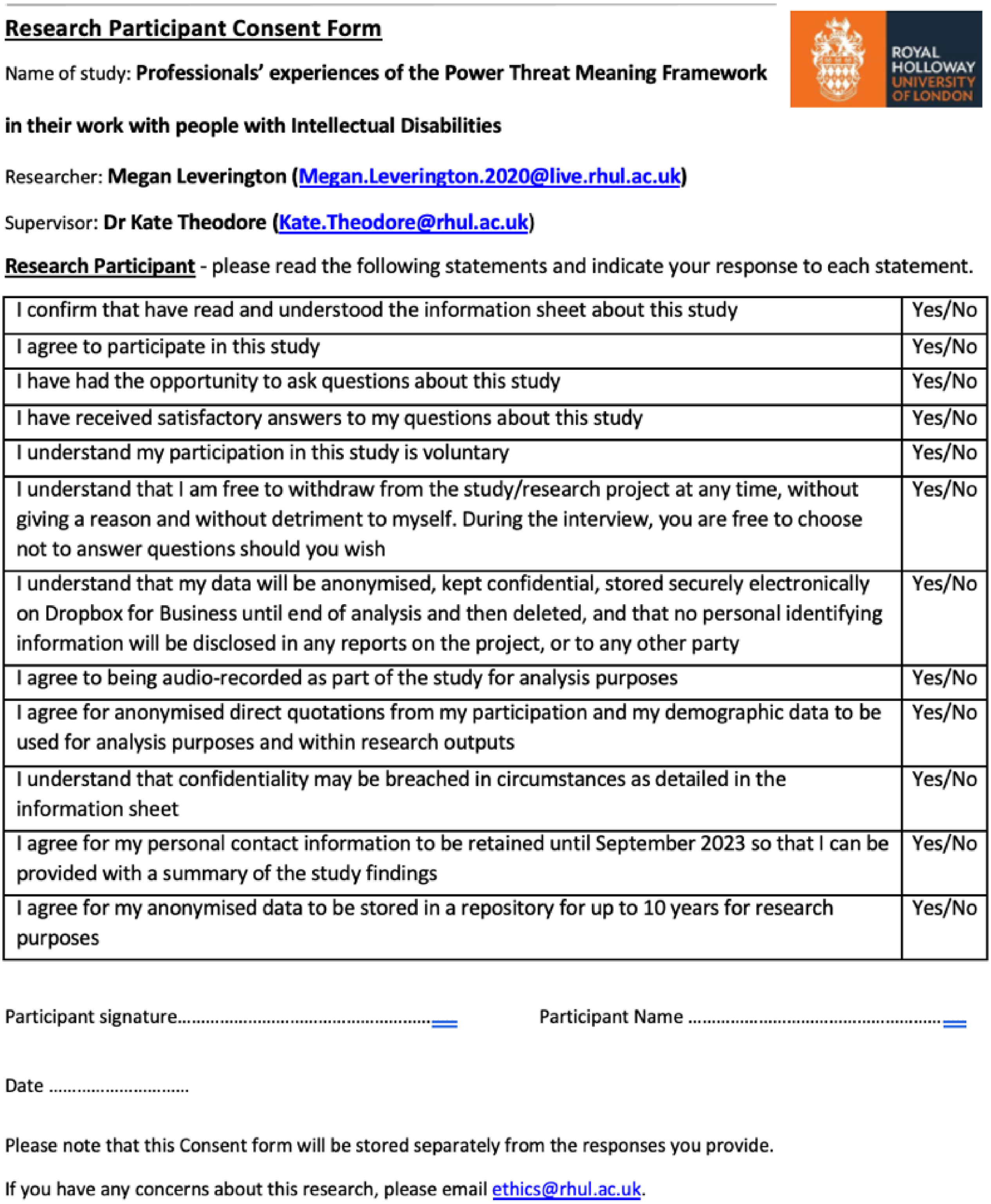
General Data Protection Regulation Statement

Important General Data Protection Regulation information (GDPR). Royal Holloway, University of London is the sponsor for this study and is based in the UK. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Any data you provide during the completion of the study will be stored securely on hosted on servers within the European Economic Area'. Royal Holloway is designated as a public authority and in accordance with the Royal Holloway and Bedford New College Act 1985 and the Statutes which govern the College, we conduct research for the public benefit and in the public interest. Royal Holloway has put in place appropriate technical and organisational security measures to prevent your personal data from being accidentally lost, used or accessed in any unauthorised way or altered or disclosed. Royal Holloway has also put in place procedures to deal with any suspected personal data security breach and will notify you and any applicable regulator of a suspected breach where legally required to do so. To safeguard your rights, we will use the minimum personally-identifiable information possible (i.e., the email address you provide us). The lead researcher will keep your contact details confidential and will use this information only as required (i.e., to provide a summary of the study results if requested and/or for the prize draw). The lead researcher will keep information about you and data gathered from the study, the duration of which will depend on the study. Certain individuals from RHUL may look at your research records to check the accuracy of the research study. If the study is published in a relevant peer-reviewed journal, the anonymised data may be made available to third parties. The people who analyse the information will not be able to identify you. You can find out more about your rights under the GDPR and Data Protection Act 2018 by visiting https://www.royalholloway.ac.uk/about-us/more/governance-and-strategy/data-protection/ and if you wish to exercise your rights, please contact dataprotection@royalholloway.ac.uk

NB: You may retain this information sheet for reference and contact us with any queries.

Appendix G

Participant consent form



Research Participant Consent Form

Name of study: **Professionals' experiences of the Power Threat Meaning Framework in their work with people with Intellectual Disabilities**

Researcher: **Megan Leverington (Megan.Leverington.2020@live.rhul.ac.uk)**

Supervisor: **Dr Kate Theodore (Kate.Theodore@rhul.ac.uk)**

Research Participant - please read the following statements and indicate your response to each statement.

I confirm that have read and understood the information sheet about this study	Yes/No
I agree to participate in this study	Yes/No
I have had the opportunity to ask questions about this study	Yes/No
I have received satisfactory answers to my questions about this study	Yes/No
I understand my participation in this study is voluntary	Yes/No
I understand that I am free to withdraw from the study/research project at any time, without giving a reason and without detriment to myself. During the interview, you are free to choose not to answer questions should you wish	Yes/No
I understand that my data will be anonymised, kept confidential, stored securely electronically on Dropbox for Business until end of analysis and then deleted, and that no personal identifying information will be disclosed in any reports on the project, or to any other party	Yes/No
I agree to being audio-recorded as part of the study for analysis purposes	Yes/No
I agree for anonymised direct quotations from my participation and my demographic data to be used for analysis purposes and within research outputs	Yes/No
I understand that confidentiality may be breached in circumstances as detailed in the information sheet	Yes/No
I agree for my personal contact information to be retained until September 2023 so that I can be provided with a summary of the study findings	Yes/No
I agree for my anonymised data to be stored in a repository for up to 10 years for research purposes	Yes/No

Participant signature………………………………………………… Participant Name ………………………………………………

Date ……………………………

Please note that this Consent form will be stored separately from the responses you provide.

If you have any concerns about this research, please email ethics@rhul.ac.uk.

Appendix H

Participant demographic questionnaire on Qualtrics

PTMF ID Professionals Project Demographic Questionnaire

Start of Block: Default Question Block

Q1 What is your age (in years)?

____

Q2 To which gender identity do you most identify?

____

Q3 How would you best describe your ethnic identity/ethnicity?

____

Q4 What is your professional title?

____

Q5 What is your highest level of education?

____

Q6 What is your current professional role and band (if within the NHS)?

____

Q7 What type of service are you currently working in (e.g., Community LD, Forensic LD, Inpatient LD, etc.)?

____

Q10 Please list any other previous types of service(s) you have worked in with adults with intellectual disabilities, if any?

____

Q8 How many years of experience do you have working with adults with intellectual disabilities?

____

Q9 How long (approximately) have you been drawing on the PTMF in your work with adults with intellectual disabilities (in months)?

____

End of Block: Default Question Block

Appendix I

Extract of familiarisation notes from phase 1 of reflexive thematic analysis

General thoughts after familiarising with data:

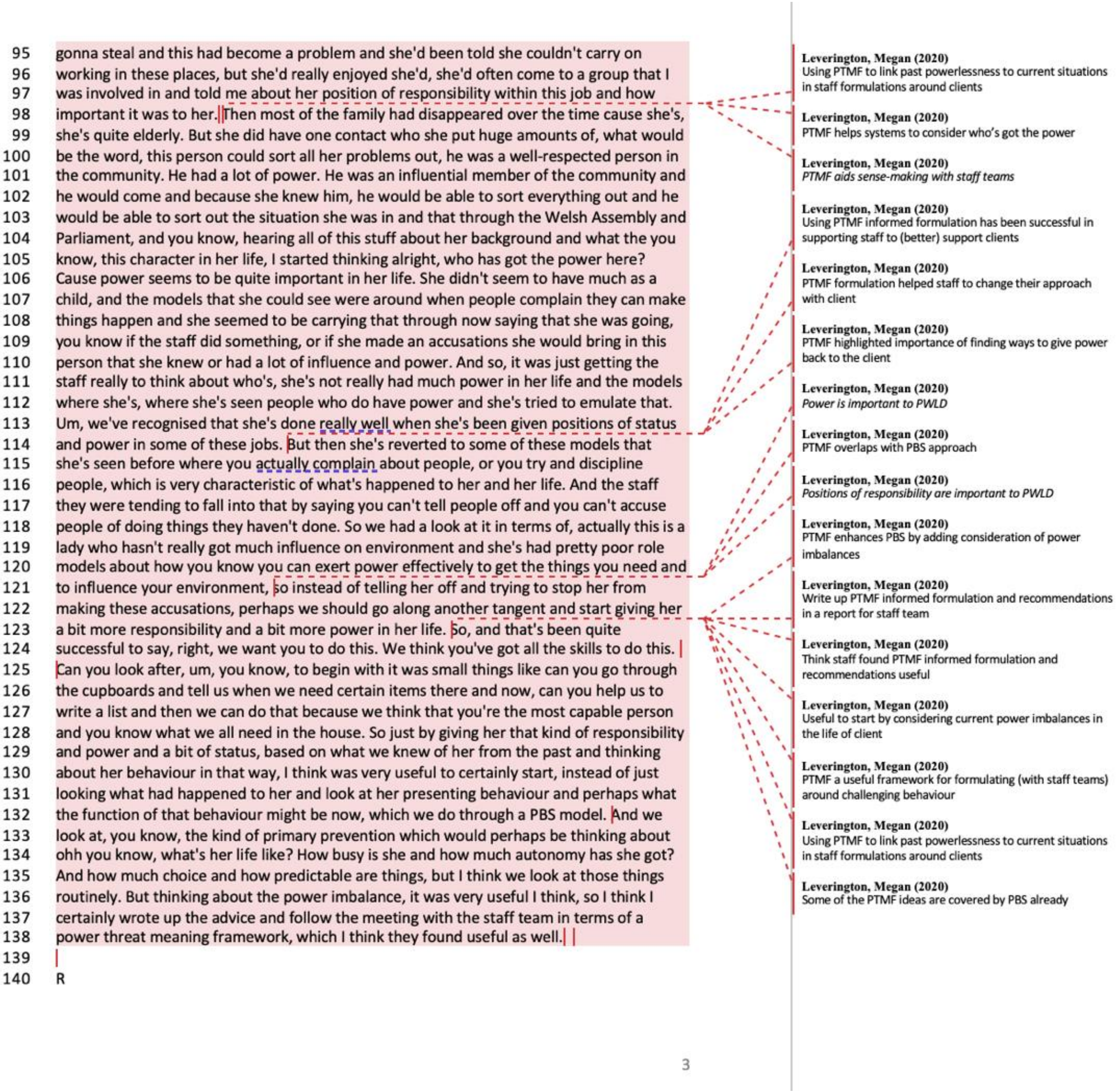
- *So incredibly complex, feeling beyond my realm of understanding / being able to make sense of… a sense of overwhelm!*
- *Consistent idea from first 2 interviews – the PTMF facilitates a conversation overtly about power*
- *Lots about power part of the PTMF being a particular enhancement to other models/frameworks etc (including PBS)*
- *Got upset/tearful reading an excerpt from ppt 4 – 'These are often just ways of coping with adverse things, thoughts of things that have happened in their environment. And you've got to go back and have a look at that and think about, what's happened? You know, and, how would you cope with that? You know, would you be able to access help? Were they able to access help? Was there a sympathetic ear there? Was there somebody who's prepared to listen to their story?"*

  Highlighting just what an emotional topic this really is, and really feeling connected to the stories of the clients being told and the passion professionals' have for the PTMF
- *Feeling very emotional again listening back to ppt 4 interview, recounts men in a group saying support workers are always right, they are always wrong. Thinking of the power I have, or people perceive me to have as a clinician, especially holding in mind the people I met during my time working within LD team*
- *Something coming up for me about PTMF being most helpful when considered at a systemic level, not in direct work, because that could leave people reflecting on powerlessness but not able to independently act on it*
- *Struck me that no one has shared thinking explicitly with MDT / wanted to present to the MDT? Kind of kept within psychology? Kept to self? All participants were the only professional using it within the team.*
- *Sensing awkwardness listening back to interview 7 as opposed to my own views – need to hold this in mind and reflect with Kate*
- *Telling story (PTMF questions) can be emotional and too difficult*
- *Not sure what meant to do with PTMF as a clinical intervention? Is it a narrative approach? How does it inform formulation (theoretically) to outline intervention points based on theory?*
- *A complementary framework would've gone down better (and is very valuable) in one ppts view rather than alternative to diagnostic frameworks*
- *Topics around clinical trials with people with LD and evidence research; one ppt disagrees with discourse around individual experience moving away from trials /'science' etc – kind of goes against my positioning as a researcher for this project which felt uncomfortable*

Ending familiarisation taken aback by the richness of a fairly small sample but large data set – could probably speak to other research questions – made me think perhaps the interview schedule wasn't focused enough? Or that's just me being self-critical and maybe the nature of this topic is just rich and complex

Appendix J

Example extract of data coding



gonna steal and this had become a problem and she'd been told she couldn't carry on working in these places, but she'd really enjoyed she'd, she'd often come to a group that I was involved in and told me about her position of responsibility within this job and how important it was to her. Then most of the family had disappeared over the time cause she's, she's quite elderly. But she did have one contact who she put huge amounts of, what would be the word, this person could sort all her problems out, he was a well-respected person in the community. He had a lot of power. He was an influential member of the community and he would come and because she knew him, he would be able to sort everything out and he would be able to sort out the situation she was in and that through the Welsh Assembly and Parliament, and you know, hearing all of this stuff about her background and what the you know, this character in her life, I started thinking alright, who has got the power here? Cause power seems to be quite important in her life. She didn't seem to have much as a child, and the models that she could see were around when people complain they can make things happen and she seemed to be carrying that through now saying that she was going, you know if the staff did something, or if she made an accusations she would bring in this person that she knew or had a lot of influence and power. And so, it was just getting the staff really to think about who's, she's not really had much power in her life and the models where she's, where she's seen people who do have power and she's tried to emulate that. Um, we've recognised that she's done really well when she's been given positions of status and power in some of these jobs. But then she's reverted to some of these models that she's seen before where you actually complain about people, or you try and discipline people, which is very characteristic of what's happened to her and her life. And the staff they were tending to fall into that by saying you can't tell people off and you can't accuse people of doing things they haven't done. So we had a look at it in terms of, actually this is a lady who hasn't really got much influence on environment and she's had pretty poor role models about how you know you can exert power effectively to get the things you need and to influence your environment, so instead of telling her off and trying to stop her from making these accusations, perhaps we should go along another tangent and start giving her a bit more responsibility and a bit more power in her life. So, and that's been quite successful to say, right, we want you to do this. We think you've got all the skills to do this. Can you look after, um, you know, to begin with it was small things like can you go through the cupboards and tell us when we need certain items there and now, can you help us to write a list and then we can do that because we think that you're the most capable person and you know what we all need in the house. So just by giving her that kind of responsibility and power and a bit of status, based on what we knew of her from the past and thinking about her behaviour in that way, I think was very useful to certainly start, instead of just looking what had happened to her and look at her presenting behaviour and perhaps what the function of that behaviour might be now, which we do through a PBS model. And we look at, you know, the kind of primary prevention which would perhaps be thinking about ohh you know, what's her life like? How busy is she and how much autonomy has she got? And how much choice and how predictable are things, but I think we look at those things routinely. But thinking about the power imbalance, it was very useful I think, so I think I certainly wrote up the advice and follow the meeting with the staff team in terms of a power threat meaning framework, which I think they found useful as well.

R

Leverington, Megan (2020)
Using PTMF to link past powerlessness to current situations in staff formulations around clients

Leverington, Megan (2020)
PTMF helps systems to consider who's got the power

Leverington, Megan (2020)
PTMF aids sense-making with staff teams

Leverington, Megan (2020)
Using PTMF informed formulation has been successful in supporting staff to (better) support clients

Leverington, Megan (2020)
PTMF formulation helped staff to change their approach with client

Leverington, Megan (2020)
PTMF highlighted importance of finding ways to give power back to the client

Leverington, Megan (2020)
Power is important to PWLD

Leverington, Megan (2020)
PTMF overlaps with PBS approach

Leverington, Megan (2020)
Positions of responsibility are important to PWLD

Leverington, Megan (2020)
PTMF enhances PBS by adding consideration of power imbalances

Leverington, Megan (2020)
Write up PTMF informed formulation and recommendations in a report for staff team

Leverington, Megan (2020)
Think staff found PTMF informed formulation and recommendations useful

Leverington, Megan (2020)
Useful to start by considering current power imbalances in the life of client

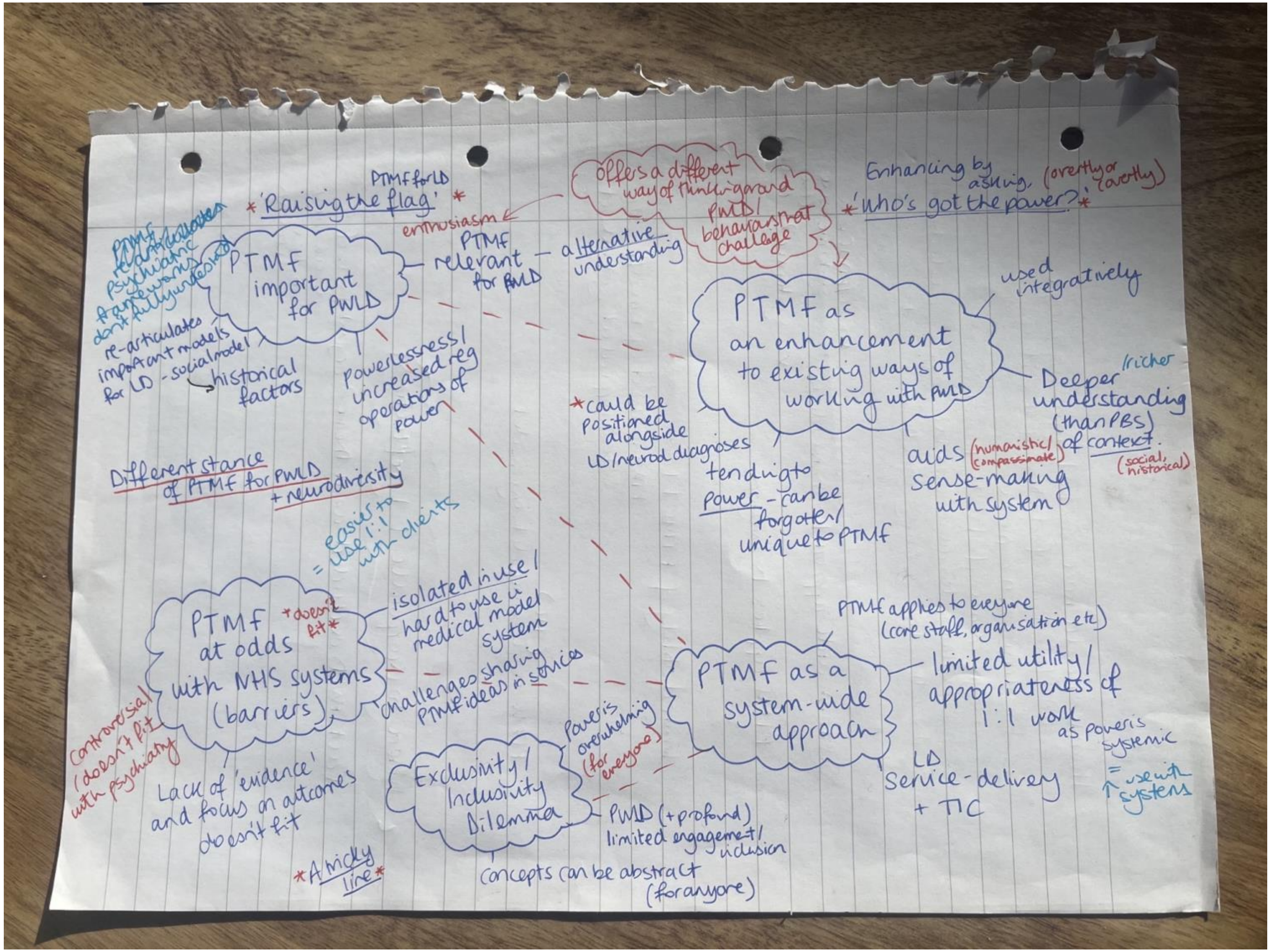
Leverington, Megan (2020)
PTMF a useful framework for formulating (with staff teams) around challenging behaviour

Leverington, Megan (2020)
Using PTMF to link past powerlessness to current situations in staff formulations around clients

Leverington, Megan (2020)
Some of the PTMF ideas are covered by PBS already

Appendix K

Initial visual mapping of themes and subthemes in phase 4 of reflexive thematic analysis



Appendix L

Draft table of themes for seeking member reflections

Participant Reflections

Professionals’ experiences of the Power Threat Meaning Framework in their work with people with Intellectual Disabilities.

Theme	Subthemes	Example codes
1. **The PTMF fits and is important for working with people with LD** *“Raising the flag” for PTMF and people with LD* *or* *Can the PTMF “raise the flag” for people with LD*	People with LD are one of the most powerless groups in society (disempowered?)	People with LD are often powerless in influencing their environment Examples of negative operations of power for people with LD are plentiful The powerlessness people with LD experience is upsetting
	Re-articulates and validates important ideas for people with LD	PTMF has validated a way of being as an LD psychologist PTMF aligns with social model of disability PTMF puts new language to existing ways of thinking about and working with people with
	There are problems with diagnostic frameworks for people with LD	Psychiatric diagnoses reduce people with LD down People with LD are misunderstood (by diagnostic frameworks) Diagnoses don’t meaningfully explain people with LDs behaviour People with LDs threat responses can be over-medicated

The first theme illustrates a general sense expressed by participants that the PTMF is fitting and important for people with LD and within their work in LD contexts. This relevance was largely interpreted from a consistent recognition that people with LD are disempowered in many aspects of their lives and face endless negative operations of power and that the PTMF re-articulates existing influential ideas for people with LD, such as the social model of disability, and validates working in line with these professional values. This perceived validation was accompanied by an acknowledgement that there are shortcomings with diagnostic frameworks for people with LD in terms of their utility in meaningfully making sense alongside people with LD, which can problematically result in the misunderstanding and over-medication of people with LD.

Theme	Subthemes	Example codes
2. **The PTMF enhances existing ways of working with people with LD** *Enhancing by asking, "who's got the power?"* *or* *Enhancing by asking, "what's happened to this person?"*	Tending to power imbalances	PTMF as a tool to explicitly consider power imbalances PTMF emphasises power (imbalances) in a novel way Power imbalances aren't ordinarily considered in LD services
	PTMF develops deeper understanding of context (and people with LD) I'm considering condensing these to 'Deeper understanding of context aids compassion' to illustrate the journey from deeper understanding to enhanced compassion / empathy	PTMF as a tool to consider social and historical context PTMF considers people with LDs behaviour in relation to what's happened to them PTMF adds a richer understanding of 'why' to PBS
	PTMF aids compassionate sense-making with systems (PTMF promotes compassionate care) *"Put yourself in shoes of PWLD"*	PTMF enhances peoples' empathy and compassion for people with LD PTMF normalises people with LDs responses in a humanistic way PTMF as non-blaming by centralising issues as social and environmental
	PTMF best positioned alongside (neurodiversity) diagnoses (PTMF and neurodiversity as both-and)	PTMF could give the impression that neurodiversity diagnoses are not valid Considering PTMF and neurodiversity diagnoses from both-and perspective PTMF can provide additional understanding around diagnoses

The second theme was generated from a pattern of meaning which suggested the PTMF offers an enhancement to existing ways of working with people with LD and in LD contexts. A focus on the power part of the PTMF was particularly resonant, with participants' appreciating the PTMF as a tool to explicitly tend to power in their work with people with LD, which may otherwise be overlooked. Through tending to power imbalances and what had happened to a person, the PTMF was perceived to facilitate a deeper understanding of the wider context than existing models such as PBS, which in turn allows for a richer, more compassionate understanding of people with LD. Linked with this, there was some acknowledgement of the importance of positioning the PTMF alongside neurodiversity diagnoses, including genetic conditions, to enhance an individualised understanding of the person.

Theme	Subthemes	Example codes
3. **PTMF as a system-wide approach** *“PTMF addresses systems of power, so needs to be applied at system level”*	PTMF applies to everyone	Staff experience parallel power imbalances to people with LD PTMF can help to consider staffs own experiences and responses PTMF means professionals must look at themselves as part of the power imbalances Professionals are impacted by organisational power
	Limited utility of PTMF 1-1 and a focus on the system (at the expense of exclusivity) Inclusivity / exclusivity dilemma	A sense of ‘so what’ after developing PTMF formulation with people with LD Power imbalances for people with LD are systemic People with profound LDs story told through lens of the system Drawing on PTMF 1-1 for people with LD gives system the impression client needs to change
	Opportunities for PTMF as a service delivery model in LD services	PTMF fits with culture shift towards trauma-informed care (TIC) in LD services LD services could lead on implementation of PTMF Ideally would start with PTMF formulation for each client when they meet with LD service Would be interesting to use PTMF as service delivery model and evaluate outcomes for people with LD

The third theme captures an interpreted pattern of meaning around the PTMF being best implemented at a systemic and system-wide level for people with LD and their systems. Participants reflected that whilst drawing on the PTMF to formulate with MDTs and care staff it was essential and helpful to consider everyone, emphasising that systems of power are pervasive and impact on us all. Primarily drawing on the PTMF indirectly with systems, participants expressed reservations around the utility of PTMF in 1-1 work, which implied an inclusivity vs exclusivity dilemma around PTMF for people with LD. Considering this, participants’ offered ideas around the PTMF being implemented as a service delivery model, aligning with the TIC movement, such as supporting people with LD to be as included as possible in developing their PTMF formulation to be shared with their system, with hopes to improve various aspects of their care (and to evaluate this with outcome research).

Theme	Subthemes	Example codes
4. **PTMF at odds with LD service systems** *"Slowly chipping away / filtering through the nuts and bolts"* *"Not wanting to come in all guns blazing with PTMF"*	PTMF doesn't fit with traditional NHS systems	PTMF is about getting it right, services currently focused on doing it right Hard to draw on PTMF in services underpinned by medical model Current NHS climate is a barrier to drawing on PTMF at service / organisational level
	Lack of focus on outcome data and empirical evidence doesn't fit	Nuances of drawing on PTMF with people with LD is hard to measure Services are often outcome driven and want tangible evidence of change Clinical trials for people with LD may not align with PTMF values
	Challenges sharing PTMF ideas within systems	Talking about power can be tense Haven't explicitly shared PTMF by name with colleagues PTMF ideas are abstract to some professionals Its isolating being the professional advocating for an alternative understanding
	PTMF causes controversy / has been divisive	There is interdisciplinary rivalry about how to understand human distress PTMF ideas can be confronting for people as highlights world can be threatening The PTMF has been interpreted as divisive

The final theme encapsulates that whilst the PTMF was considered more of a system-wide approach, participants highlighted an array of barriers to implementation at an organisational level. Generally, there was a shared sense that the PTMF doesn't fit with traditional NHS systems, especially the lack of focus on empirical evidence and potential complexities of measuring outcomes in a meaningful way. Inferred as a result of this lack of fit, most participants expressed various challenges sharing PTMF ideas within systems and how this feels, which has been interpreted as a sense of isolation (perhaps even loneliness) in thinking and practicing in line with PTMF values. Linked with this, all participants acknowledged the controversy surrounding the PTMF and most situated the divisiveness as the result of interdisciplinary rivalry with psychiatry and the confronting, yet important, nature of the PTMF ideas, ultimately leaving the framework at odds with LD service systems.

Overarching theme

PTMF has a contribution to offer working with people with LD and their systems

I have been considering this as an overarching theme that I feel runs through and ties together the four themes and their subthemes. The majority of participants referenced the paradigm shift away from psychiatric diagnoses offered by the PTMF, and the usefulness of considering what has happened to a person when working supportively with people with LD and their systems. The felt sense and explicit expression of enthusiasm for this different, non-pathologising, normalising and compassionate stance was immense throughout the interviews. Ultimately, participants appeared to be advocating that people's (societies, organisations, professionals, and families) views of people with LD need to be supportively questioned and positively reformed, and the PTMF could help with this… if we could find a way for it to fit harmoniously.

Appendix M

Email to all participants to invite participant reflections

Dear Participant,

I hope you have been well since we met late last year, and you very kindly took the time to participate in my research exploring professionals' experiences and perspectives on the PTMF for people with LD.

I'm getting in touch again as I have been working on the analysis from the interviews and am really keen to get your reflections on the draft themes / analytic story that I've interpreted from the 8 professionals' I interviewed, including yourself. Please find attached a draft table of themes and subthemes with a theme description and a draft visual thematic map. For context, I'm drawing on reflexive thematic analysis methodology, which focuses on my subjective interpretations of salient patterns of meaning across the dataset to form an analytic narrative that addresses the research questions *(1. What are professionals' perspectives and experiences of the actual and potential applications of the PTMF for adults with ID and their systems?' and 'what do professionals perceive to be the strengths and limitations of drawing on the PTMF for adults with ID and their systems?).* Everyone's contributions within the interviews were so rich that many analytic stories could have been generated from the dataset, highlighting this is just one story that I have interpreted within the data.

I'm hoping to gather and incorporate participant reflections, rather than traditional credibility checks to 'validate' findings, to gain reflexive elaboration on the analysis as this more closely aligns with my epistemological position and underlying research values. If you are able and would like to provide your reflections on the analysis, I invite you to please reflect on any of the following (or anything else you think is relevant) whilst reviewing the draft analysis / themes:

- What do you think about the analysis? E.g., Do you find the provisional themes / results interesting? Enlightening? Objectionable?
- What are your thoughts on whether / how much each theme resonates for you? Do you have any suggestions on each theme?
- Importantly, I am still in the process of choosing names / wording for each theme and subtheme title, so it would be great if you'd like to **please provide reflections / suggestions for titles of themes and whether you feel the draft titles capture the overall theme?** For the main theme names, I am considering using salient phrases / quotes from participant contributions, provisional ideas for which are include within the table in italic.
- Is there anything else you want to comment / reflect on overall?

If you would like to kindly offer your reflections on my analysis, I would ask that you **please respond by end of Monday 27thMarch** (in one weeks' time). Apologies for the tight turnaround, unfortunately I'm on a very time limited schedule with my thesis deadline fast approaching and it's important to me that I have enough time to meaningfully include any reflections you provide in my write-up. Any format of reflections will be much appreciated – whether that's as review comments on the word doc or your reflections in an email! Unfortunately, if I do not hear back from you by next week I will have to move on with my analysis without your valuable reflections.

Many thanks in advance and I'm really looking forward to hearing your thoughts!

Best wishes,
Megan

Appendix N

Example extracts from participant member reflections

Participant 8: *"Well done! I have one comment to share. My sense of LD services is that they also don't fit with traditional NHS services, or NHS mental health services as they stand now. Traditionally PWLD were institutionalised, and current MH services use pathways that are defined by MH diagnoses…"*

Participant 5: *"This is all excellent – I was very intrigued to see what others had said and how you would summarise the themes. I like that you have used some quotes within the themes. The analysis is really good and balanced with some downsides and negatives included – is there a space to include a 'what's interesting from the results' section. The themes do resonate and represent my views and thoughts well"*

Participant 2: *"I am not surprised that this is a significant theme in your research, Megan. I just nodded as I read the 'subthemes' and wondered how to reflect that here. Absolutely … Yes! Who is going to take it forward? Will psychologists stand up and speak truth to power or is professional harmony more important? What will psychologists / AHPs do in a context where they believe they are less powerful than those espousing the dominant paradigm? I think this takes moral courage and systematic restructuring of services by brave managers and senior clinicians to create a powerful alternative culture to that which is considered to reinforce inequality and oppression. It makes me wonder about the level of context at which this change needs to happen for people to really challenge treatment as usual."*

Participant 7: *"Thanks for sending through. I am trying to be helpful, rather than critical - what came across initially was a sense that PTMF is inherently positive and needed due to a lack of "something"; those who are critical, or the systems in which we work are problematic as opposed to the possibility that there are problems with PTMF. This suggests some concern to me. I wondered whether greater balance was needed?"*

Participant 3: *"Thanks for sending the results through - I didn't really have much to comment on to be honest - I've attached the analysis with a couple of comments. This might not be an example code but just a thought about how people with LD are often involved in a complex array of systems, which aren't just NHS, but social care, independent care providers etc so this there are many organisational barriers and interfaces which I think increases the complexity that professionals working in one context e.g., NHS might have little influence over as well."*

Appendix O

Data-charting form

Evidence source details and characteristics	
Citation details (author(s), date, title, journal, volume, issues, pages)	
Country (Origin, where the study was published or conducted)	
Context (Setting)	
Participants (Demographics, sample size, which IDD population if specified, individual with IDD, parent/carer or professionals *In which contexts and with which specific IDD populations have TIC approaches been applied?*)	
Details/results extracted from source of evidence	
Focus of study (aims/purpose)	
Methodology/study design (How is research conducted on TIC in the context of IDD?)	

Key findings related to scoping review questions (What are the characteristics of TIC approaches in the context of IDD? What outcomes have been reported in the literature when testing or implementing TIC for people with IDD? What are the knowledge gaps regarding TIC in the context of IDD?)	
MMAT score	
Any additional data related to the scoping review objectives	

Appendix P

The Mixed Methods Appraisal Tool (MMAT)

Supplementary File 3: Methodological Quality Appraisal Tool

MIXED METHODS APPRAISAL TOOL (MMAT) VERSION 2018

User guide

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Department of Family Medicine
Département de médecine de famille
Academic excellence and innovation in care, teaching and research
Innovation et excellence académique dans les soins, l'enseignement et la recherche

Last update: August 1st, 2018

What is the MMAT?

The MMAT is a critical appraisal tool that is designed for the appraisal stage of systematic mixed studies reviews, i.e., reviews that include qualitative, quantitative and mixed methods studies. It permits to appraise the methodological quality of five categories to studies: qualitative research, randomized controlled trials, non-randomized studies, quantitative descriptive studies, and mixed methods studies.

How was the MMAT developed?

The MMAT was developed in 2006 (Pluye et al., 2009a) and was revised in 2011 (Pace et al., 2012). The present version 2018 was developed on the basis of findings from a literature review of critical appraisal tools, interviews with MMAT users, and an e-Delphi study with international experts (Hong, 2018). The MMAT developers are continuously seeking for improvement and testing of this tool. Users' feedback is always appreciated.

What the MMAT can be used for?

The MMAT can be used to appraise the quality of empirical studies, i.e., primary research based on experiment, observation or simulation (Abbott, 1998; Porta et al., 2014). It cannot be used for non-empirical papers such as review and theoretical papers. Also, the MMAT allows the appraisal of most common types of study methodologies and designs. However, some specific designs such as economic and diagnostic accuracy studies cannot be assessed with the MMAT. Other critical appraisal tools might be relevant for these designs.

What are the requirements?

Because critical appraisal is about judgment making, it is advised to have at least two reviewers independently involved in the appraisal process. Also, using the MMAT requires experience or training in these domains. For instance, MMAT users may be helped by a colleague with specific expertise when needed.

How to use the MMAT?

This document comprises two parts: checklist (Part I) and explanation of the criteria (Part II).

1. Respond to the two screening questions. Responding 'No' or 'Can't tell' to one or both questions might indicate that the paper is not an empirical study, and thus cannot be appraised using the MMAT. MMAT users might decide not to use these questions, especially if the selection criteria of their review are limited to empirical studies.
2. For each included study, choose the appropriate category of studies to appraise. Look at the description of the methods used in the included studies. If needed, use the algorithm at the end of this document.
3. Rate the criteria of the chosen category. For example, if the paper is a qualitative study, only rate the five criteria in the qualitative category. The 'Can't tell' response category means that the paper do not report appropriate information to answer 'Yes' or 'No', or that report unclear information related to the criterion. Rating 'Can't tell' could lead to look for companion papers, or contact authors to ask more information or clarification when needed. In Part II of this document, indicators are added for some criteria. The list is not exhaustive and not all indicators are necessary. You should agree among your team which ones are important to consider for your field and apply them uniformly across all included studies from the same category.

How to score?

It is discouraged to calculate an overall score from the ratings of each criterion. Instead, it is advised to provide a more detailed presentation of the ratings of each criterion to better inform the quality of the included studies. This may lead to perform a sensitivity analysis (i.e., to consider the quality of studies by contrasting their results). Excluding studies with low methodological quality is usually discouraged.

How to cite this document?

Hong QN, Pluye P, Fàbregues S, Bartlett G, Boardman F, Cargo M, Dagenais P, Gagnon M-P, Griffiths F, Nicolau B, O'Cathain A, Rousseau M-C, Vedel I. Mixed Methods Appraisal Tool (MMAT), version 2018. Registration of Copyright (#1148552), Canadian Intellectual Property Office, Industry Canada.

Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

Part II: Explanations

1. Qualitative studies	**Methodological quality criteria**
"Qualitative research is an approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem" (Creswell, 2013b, p. 3). Common qualitative research approaches include (this list if not exhaustive): **Ethnography** The aim of the study is to describe and interpret the shared cultural behaviour of a group of individuals. **Phenomenology** The study focuses on the subjective experiences and interpretations of a phenomenon encountered by individuals. **Narrative research** The study analyzes life experiences of an individual or a group. **Grounded theory** Generation of theory from data in the process of conducting research (data collection occurs first). **Case study** In-depth exploration and/or explanation of issues intrinsic to a particular case. A case can be anything from a decision-making process, to a person, an organization, or a country. **Qualitative description** There is no specific methodology, but a qualitative data collection and analysis, e.g., in-depth interviews or focus groups, and hybrid thematic analysis (inductive and deductive). Key references: Creswell (2013a); Sandelowski (2010); Schwandt (2015)	1.1. Is the qualitative approach appropriate to answer the research question? Explanations The qualitative approach used in a study (see non-exhaustive list on the left side of this table) should be appropriate for the research question and problem. For example, the use of a grounded theory approach should address the development of a theory and ethnography should study human cultures and societies. This criterion was considered important to add in the MMAT since there is only one category of criteria for qualitative studies (compared to three for quantitative studies).
	1.2. Are the qualitative data collection methods adequate to address the research question? Explanations This criterion is related to data collection method, including data sources (e.g., archives, documents), used to address the research question. To judge this criterion, consider whether the method of data collection (e.g., in depth interviews and/or group interviews, and/or observations) and the form of the data (e.g., tape recording, video material, diary, photo, and/or field notes) are adequate. Also, clear justifications are needed when data collection methods are modified during the study.
	1.3. Are the findings adequately derived from the data? Explanations This criterion is related to the data analysis used. Several data analysis methods have been developed and their use depends on the research question and qualitative approach. For example, open, axial and selective coding is often associated with grounded theory, and within- and cross-case analysis is often seen in case study.
	1.4. Is the interpretation of results sufficiently substantiated by data? Explanations The interpretation of results should be supported by the data collected. For example, the quotes provided to justify the themes should be adequate.
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation? Explanations There should be clear links between data sources, collection, analysis and interpretation.

3. Quantitative non-randomized studies	**Methodological quality criteria**
Non-randomized studies are defined as any quantitative studies estimating the effectiveness of an intervention or studying other exposures that do not use randomization to allocate units to comparison groups (Higgins and Green, 2008). Common designs include (this list if not exhaustive): **Non-randomized controlled trials** The intervention is assigned by researchers, but there is no randomization, e.g., a pseudo-randomization. A non-random method of allocation is not reliable in producing alone similar groups. **Cohort study** Subsets of a defined population are assessed as exposed, not exposed, or exposed at different degrees to factors of interest. Participants are followed over time to determine if an outcome occurs (prospective longitudinal). **Case-control study** Cases, e.g., patients, associated with a certain outcome are selected, alongside a corresponding group of controls. Data is collected on whether cases and controls were exposed to the factor under study (retrospective). **Cross-sectional analytic study** At one particular time, the relationship between health-related characteristics (outcome) and other factors (intervention/exposure) is examined. E.g., the frequency of outcomes is compared in different population subgroups according to the presence/absence (or level) of the intervention/exposure. Key references for non-randomized studies: Higgins and Green (2008); Porta et al. (2014); Sterne et al. (2016); Wells et al. (2000)	3.1. Are the participants representative of the target population? Explanations Indicators of representativeness include: clear description of the target population and of the sample (inclusion and exclusion criteria), reasons why certain eligible individuals chose not to participate, and any attempts to achieve a sample of participants that represents the target population.
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? Explanations Indicators of appropriate measurements include: the variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; the measurements reflect what they are supposed to measure; validated and reliability tested measures of the intervention/exposure and outcome of interest are used, or variables are measured using 'gold standard'.
	3.3. Are there complete outcome data? Explanations Almost all the participants contributed to almost all measures. There is no absolute and standard cut-off value for acceptable complete outcome data. Agree among your team what is considered complete outcome data in your field (and based on the targeted journal) and apply this uniformly across all the included studies. For example, in the literature, acceptable complete data value ranged from 80% (Thomas et al., 2004; Zaza et al., 2000) to 95% (Higgins et al., 2016). Similarly, different acceptable withdrawal/dropouts rates have been suggested: 5% (de Vet et al., 1997; MacLehose et al., 2000), 20% (Sindhu et al., 1997; Van Tulder et al., 2003) and 30% for follow-up of more than one year (Viswanathan and Berkman, 2012).
	3.4. Are the confounders accounted for in the design and analysis? Explanations Confounders are factors that predict both the outcome of interest and the intervention received/exposure at baseline. They can distort the interpretation of findings and need to be considered in the design and analysis of a non-randomized study. Confounding bias is low if there is no confounding expected, or appropriate methods to control for confounders are used (such as stratification, regression, matching, standardization, and inverse probability weighting).
	3.5 During the study period, is the intervention administered (or exposure occurred) as intended? Explanations For intervention studies, consider whether the participants were treated in a way that is consistent with the planned intervention. Since the intervention is assigned by researchers, consider whether there was a presence of contamination (e.g., the control group may be indirectly exposed to the intervention) or whether unplanned co-interventions were present in one group (Sterne et al., 2016). For observational studies, consider whether changes occurred in the exposure status among the participants. If yes, check if these changes are likely to influence the outcome of interest, were adjusted for, or whether unplanned co-exposures were present in one group (Morgan et al., 2017).

4. Quantitative descriptive studies	**Methodological quality criteria**
Quantitative descriptive studies are "concerned with and designed only to describe the existing distribution of variables without much regard to causal relationships or other hypotheses" (Porta et al., 2014, p. 72). They are used to monitoring the population, planning, and generating hypothesis (Grimes and Schulz, 2002). Common designs include the following single-group studies (this list if not exhaustive): **Incidence or prevalence study without comparison group** In a defined population at one particular time, what is happening in a population, e.g., frequencies of factors (importance of problems), is described (portrayed). **Survey** "Research method by which information is gathered by asking people questions on a specific topic and the data collection procedure is standardized and well defined." (Bennett et al., 2011, p. 3). **Case series** A collection of individuals with similar characteristics are used to describe an outcome. **Case report** An individual or a group with a unique/unusual outcome is described in detail. Key references: Critical Appraisal Skills Programme (2017); Draugalis et al. (2008)	4.1. Is the sampling strategy relevant to address the research question? Explanations Sampling strategy refers to the way the sample was selected. There are two main categories of sampling strategies: probability sampling (involve random selection) and non-probability sampling. Depending on the research question, probability sampling might be preferable. Non-probability sampling does not provide equal chance of being selected. To judge this criterion, consider whether the source of sample is relevant to the target population; a clear justification of the sample frame used is provided; or the sampling procedure is adequate.
	4.2. Is the sample representative of the target population? Explanations There should be a match between respondents and the target population. Indicators of representativeness include: clear description of the target population and of the sample (such as respective sizes and inclusion and exclusion criteria), reasons why certain eligible individuals chose not to participate, and any attempts to achieve a sample of participants that represents the target population.
	4.3. Are the measurements appropriate? Explanations Indicators of appropriate measurements include: the variables are clearly defined and accurately measured, the measurements are justified and appropriate for answering the research question; the measurements reflect what they are supposed to measure; validated and reliability tested measures of the outcome of interest are used, variables are measured using 'gold standard', or questionnaires are pre-tested prior to data collection.
	4.4. Is the risk of nonresponse bias low? Explanations Nonresponse bias consists of "an error of nonobservation reflecting an unsuccessful attempt to obtain the desired information from an eligible unit." (Federal Committee on Statistical Methodology, 2001, p. 6). To judge this criterion, consider whether the respondents and non-respondents are different on the variable of interest. This information might not always be reported in a paper. Some indicators of low nonresponse bias can be considered such as a low nonresponse rate, reasons for nonresponse (e.g., noncontacts vs. refusals), and statistical compensation for nonresponse (e.g., imputation). The nonresponse bias is might not be pertinent for case series and case report. This criterion could be adapted. For instance, complete data on the cases might be important to consider in these designs.
	4.5. Is the statistical analysis appropriate to answer the research question? Explanations The statistical analyses used should be clearly stated and justified in order to judge if they are appropriate for the design and research question, and if any problems with data analysis limited the interpretation of the results.

5. Mixed methods studies	**Methodological quality criteria**
Mixed methods (MM) research involves combining qualitative (QUAL) and quantitative (QUAN) methods. In this tool, to be considered MM, studies have to meet the following criteria (Creswell and Plano Clark, 2017): (a) at least one QUAL method and one QUAN method are combined; (b) each method is used rigorously in accordance to the generally accepted criteria in the area (or tradition) of research invoked; and (c) the combination of the methods is carried out at the minimum through a MM design (defined *a priori*, or emerging) and the integration of the QUAL and QUAN phases, results, and data. Common designs include (this list if not exhaustive): **Convergent design** The QUAL and QUAN components are usually (but not necessarily) concomitant. The purpose is to examine the same phenomenon by interpreting QUAL and QUAN results (bringing data analysis together at the interpretation stage), or by integrating QUAL and QUAN datasets (e.g., data on same cases), or by transforming data (e.g., quantization of qualitative data). **Sequential explanatory design** Results of the phase 1 - QUAN component inform the phase 2 - QUAL component. The purpose is to explain QUAN results using QUAL findings. E.g., the QUAN results guide the selection of QUAL data sources and data collection, and the QUAL findings contribute to the interpretation of QUAN results. **Sequential exploratory design** Results of the phase 1 - QUAL component inform the phase 2 - QUAN component. The purpose is to explore, develop and test an instrument (or taxonomy), or a conceptual framework (or theoretical model). E.g., the QUAL findings inform the QUAN data collection, and the QUAN results allow a statistical generalization of the QUAL findings. Key references: Creswell et al. (2011); Creswell and Plano Clark, (2017); O'Cathain (2010)	5.1. Is there an adequate rationale for using a mixed methods design to address the research question? Explanations The reasons for conducting a mixed methods study should be clearly explained. Several reasons can be invoked such as to enhance or build upon qualitative findings with quantitative results and vice versa; to provide a comprehensive and complete understanding of a phenomenon or to develop and test instruments (Bryman, 2006).
	5.2. Are the different components of the study effectively integrated to answer the research question? Explanations Integration is a core component of mixed methods research and is defined as the "explicit interrelating of the quantitative and qualitative component in a mixed methods study" (Plano Clark and Ivankova, 2015, p. 40). Look for information on how qualitative and quantitative phases, results, and data were integrated (Pluye et al., 2018). For instance, how data gathered by both research methods was brought together to form a complete picture (e.g., joint displays) and when integration occurred (e.g., during the data collection-analysis or/and during the interpretation of qualitative and quantitative results).
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? Explanations This criterion is related to meta-inference, which is defined as the overall interpretations derived from integrating qualitative and quantitative findings (Teddlie and Tashakkori, 2009). Meta-inference occurs during the interpretation of the findings from the integration of the qualitative and quantitative components, and shows the added value of conducting a mixed methods study rather than having two separate studies.
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? Explanations When integrating the findings from the qualitative and quantitative components, divergences and inconsistencies (also called conflicts, contradictions, discordances, discrepancies, and dissonances) can be found. It is not sufficient to only report the divergences; they need to be explained. Different strategies to address the divergences have been suggested such as reconciliation, initiation, bracketing and exclusion (Pluye et al., 2009b). Rate this criterion 'Yes' if there is no divergence.
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved? Explanations The quality of the qualitative and quantitative components should be individually appraised to ensure that no important threats to trustworthiness are present. To appraise 5.5, use criteria for the qualitative component (1.1 to 1.5), and the appropriate criteria for the quantitative component (2.1 to 2.5, or 3.1 to 3.5, or 4.1 to 4.5). The quality of both components should be high for the mixed methods study to be considered of good quality. The premise is that the overall quality of a mixed methods study cannot exceed the quality of its weakest component. For example, if the quantitative component is rated high quality and the qualitative component is rated low quality, the overall rating for this criterion will be of low quality.

Appendix Q

MMAT quality appraisal ratings for included empirical studies

Category of study design	Methodological quality criteria				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis, and interpretation?
Keesler (2016)	Yes	Yes	Yes	Yes	Yes
McNally et al. (2022)	Yes	Yes	Yes	Yes	Yes
Schofield et al. (2021)	Yes	Yes	Yes	Yes	Yes
3. Quantitative non-randomised	3.1. Are the participants representative of the target population?	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	3.3. Are there complete outcome data?	3.4. Are the confounders accounted for in the design and analysis?	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?
Power et al. (2014)	Yes	Can’t tell	No	No	Can’t tell

4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?	4.2. Is the sample representative of the target population?	4.3. Are the measurements appropriate?	4.4. Is the risk of nonresponse bias low?	4.5. Is the statistical analysis appropriate to answer the research question?
Keesler (2017)	Yes	Yes	Yes	No	Yes
Keesler (2020b)	Yes	Yes	Yes	Yes	Yes
Keesler (2020c)	Yes	Yes	Yes	Yes	Yes
Presnell et al. (2022)	Yes	Yes	Yes	Yes	Yes
5. Mixed methods	5.1 Is there an adequate rationale for using a mixed methods design to address the research question?	5.2 Are the different components of the study effectively integrated to answer the research question?	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
Keesler & Isham (2017)	No	Yes	Yes	Yes	Yes
Keesler et al. (2023)	Yes	Yes	Yes	Yes	Yes
Rich et al. (2021)	No	Yes	Yes	Yes	Yes