EXPLORING UNDERSTANDINGS OF "CHALLENGING BEHAVIOUR" IN THE CONTEXT OF PEOPLE WITH LEARNING DISABILITIES: VIEWS OF THOSE WHO REFER AND THOSE WHO RESPOND

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ABSTRACT

Challenging behaviour is a label often given to people with learning disabilities when their behaviour challenges the system around them (Department of Health, 1993). There are numerous ways of understanding challenging behaviour. Given the mutual dependence between community learning disability teams and community support services in supporting people with learning disabilities, it was considered interesting to make explicit some of the ideas and assumptions that might enable or disable teams to work in consistent ways. This study draws on the research of Haydon-Laurelut, Nunkoosing and Millett (2014) and Nunkoosing and Haydon-Laurelut (2011).

Six support workers at day centres for adults with learning disabilities (referrers) and six clinical psychologists working at community learning disability teams (responders) took part in semi-structured interviews. The interviews asked about their understandings of challenging behaviour in the context of making and receiving referrals. Interviews were transcribed verbatim and analysed using thematic analysis.

Findings suggested that the support workers and clinical psychologists had quite similar ways of understanding challenging behaviour, which was an unexpected finding. They both used dominant discourses to talk about their understandings, as well as acknowledging that challenging behaviour is a social construction. These understandings were acknowledged to occur within the system or network around the person. Although there were shared understandings, still a schism existed in terms of how the services viewed each other. It was considered that something other than 'understanding' may be at the root of these differences and the suggestion made that the impact of emotions and relationships not being fully attended to and a common sense of powerlessness in the network could be important.

Implications of the findings on an individual, service, policy and societal level were considered as well as ideas for future research. A critical review is provided in the final part of this thesis.

ACKNOWLEDGMENTS

ABBREVIATIONS

PWLD- People with Learning Disabilities

LD- Learning Disabilities

CB- Challenging Behaviour

CLDT- Community Learning Disabilities Team

CP- Clinical Psychologist

TA- Thematic Analysis

NHS- National Health Service

DoH- Department of Health

Contents

1. INTRODUCTION

Within this section I will review the literature on how challenging behaviour (CB) is understood within the learning disabilities (LD) context. In consideration of language, I will use 'people with learning disabilities' (PWLD), as it is currently the most frequently used term within services in the UK. Other terms are used internationally, and have been used historically within the UK, and they were included in the literature search. As the understanding of the construct of "challenging behaviour" is at the core of this research, the use of this term will be explored fully within this chapter. I will then explore the influence of the historical and presenting context on how CB is understood. I will consider how the dynamic between support staff and clients, and between support staff and Community Learning Disability Teams (CLDT's), influences understanding. I will also consider the relevance of attribution theory (Heider, 1958) on how support staff make sense of CB. This chapter will close with the rationale and research question for this study, in light of the literature review.

1.1. **Literature Search Strategy**

For the literature review of this research, papers were searched for electronically using EBSCOHost, (PsycINFO, PsychArticles, CINAHL Plus, Academic Search Complete), ScienceDirect, and SCOPUS. The terms and permutations used were learning disabilities, intellectual disabilities, mental retardation, challenging behaviour, staff and carers. The articles found were read and references of relevant articles and books were also reviewed, to identify articles that were missed from the search.

1.2. **Social Construction of Learning Disabilities and Challenging Behaviour**

1.2.1. Construction of Learning Disabilities

Before considering CB, it is useful to have an understanding of the group of individuals who usually receive this label and the broader labels that are

already placed upon them. When using the term PWLD, it incorporates a wide range of people with diverse abilities and needs. The most commonly used definition of LD in services is:

"Significant impairment of intellectual functioning (usually taken as IQ < 70); significant impairment of adaptive/social functioning; and age of onset before adulthood"

[British Psychological Society, 2001, p.4].

This places any difficulty within the individual. Danforth and Navarro (1998) describe how traditional constructions of LD serve to create PWLD as objects of cultural fear, to legitimise social control and silencing of their version of events. A definition that puts the problem with society seems to be a more helpful way of constructing disability:

"It is not individual's limitations...but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation"

[Oliver, 1996, p.32].

Regardless of the definition used, one consequence of obtaining an identity of LD is that the person often becomes subject to lifelong clinical support. These individuals will often spend much of their lives in settings that form unique social worlds with specified rules and ways of working. Therefore PWLD often have a narrow range of possible ways of being available to them. By acknowledging the term LD as a social construction, we can start to understand how professionals and society in general have tried to codify and construct the behaviour of PWLD in a similar way, particularly those behaviours that do not fit in with the social norm.

1.2.2. Construction of Challenging Behaviour

Observing how language and definitions shift over time is relevant in understanding how professionals and support staff make sense of and

understand CB. Prior to the term 'CB' becoming prevalent, 'problem behaviour' 'difficult behaviour' or 'socially unacceptable behaviour' were terms that were often used. These terms seem to place the behaviour as the sole property of the individual (Lowe, Felce & Blackman, 1995). The term CB was introduced as a way of encompassing anyone whose behaviour presented a challenge to services, irrespective of the cause. A person is not inherently challenging, but services can find themselves challenged by the actions of others. The term intended to highlight how the way in which someone is supported is as important as a person's individual characteristics (Department of Health, [DoH], 1993). Jim Mansell suggested that over time there has been an inappropriate drift towards using the term as an individualising label (DoH, 2007), for example, individuals being labelled directly as 'CB'.

As is often the case when terms are used to define a group of individuals, they acquire pejorative meaning over time, so new labels are created to replace problematic terms. Ephraim (1998) offered a different way of looking at things and suggested there is no such thing as CB, instead there is 'exotic communication'; the effect of a behaviour may be heard, but the message may not be listened to or understood. People who display CB are described as 'the pained the unheard and the unloved' (Ephraim, 1998, p. 210).

Many people prefer to explicitly acknowledge that CB is not something that resides within a person, nor is it the sole responsibility of the individual. Thus terms such as 'behaviour that challenges others' or 'people who services label as challenging' are sometimes used. Giving a behaviour a label of challenging does not add to our understanding of how that behaviour functions (Cullen, 1999). CB has come to be seen as part of complex social patterns, and the term 'interactional challenge' has also been used to highlight it is a difficulty with interaction between two people (Cullen, 1999). Some believe we should abandon labels altogether:

 "By abandoning labels, we shift attention from the deficiencies of the person to those of the society and service systems. Thus, we cease to ask what is wrong with the person and begin to ask what kinds of environments and

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services we can create…most important, when we abandon labels we are forced to listen to those whose perspectives we have ignored and to take what they have to say seriously"

[Bogdan & Taylor (1994), pp. 224–225].

Irrespective of how it is spoken about, there does seem to be an acknowledgement that it is helpful to have a term that acknowledges that some behavioural responses can result in a person being excluded from services or experiencing a reduction in quality of life (Ingram & Lovell, 2011), and that it is helpful to speak about it. Nunkoosing (2000) has discussed how dominant discourses of LD and CB serve to support existing structures in care environments. The prospect of having a label of CB can be seen as a double bind. It can lead to specialist assessment and intervention, but it may also lead to marginalisation and discrimination if care givers are reluctant to work towards community participation because of the behaviour (Ingram & Lovell, 2011). Thus it is easy to see how carrying a label of both LD and CB can lead to double stigma (Goffman, 1968). By referring to the construct of CB, it gives services a clear idea of what or whom they might need support with and gives CLDTs a clear remit on what they can offer in response.

For the purposes of this research I have used the term 'CB', holding in mind the ideas for which the definition was originally intended, that it is behaviour that challenges services (DoH, 1993). It is also the term used most widely in services currently. I do, however, see it as an imperfect term that cannot possibly catch the complexities of the individuals and environments it intends to define, nor should it aim to.

1.3. **Definition and Topography**

1.3.1. Definition of Challenging Behaviour

Despite there being some ambiguity in the terminology and language, there is little debate in the literature with regards to the definition used to describe such behaviours. The majority of the research on the topic of CB refers to

Emerson's (1995) definition. This focuses on the physical and social impact of CB and describes it as:

"culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities".

CB is often understood to be an interaction between a person and their environment (Bell & Espie, 2002), and thus it could be seen that it is the environment itself that is being challenged. Hastings (1997) has suggested five causal models of CB: learned behaviour, biomedical, emotional, physical environment and self-stimulation. Hastings (1995) found that the majority of staff viewed CB as caused by either a communication need, the physical environment, unhappiness or biological reasons (for example, sexual frustration or brain damage).

Wilcox, Finlay and Edmonds (2006) discuss how the biological understanding suggests individuals have disabilities or conditions that make CB more likely to occur. In this view, CB is constructed as being something that has always been there and as stable and internal to the client. Wilcox et al (2006) found the care staff interviewed all strongly highlighted this discourse in their ideas about CB. Campbell (2010) discusses the importance of not assuming that behaviours that seem challenging are connected to a person's disability. Behaviour will always serve a function for the person, and it is the role of people around the individual to identify what the function is. There are multiple factors in a person's life that might influence CB, including personal factors, such as degree of LD, sensory ability, physical and mental health difficulties, communication ability, life events, as well as environmental factors such as housing, occupation and staffing (Royal College of Psychiatrists [RCP], British Psychological Society & Royal College of Speech & Language Therapists, 2007). In order to understand CB, Ingram and Lovell (2011) suggest combining a biological understanding, with the evidence based provided by

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behavioural approaches, and then combining this with a human perspective of the interplay between an individual and their behaviour.

Hastings (1995) found staff highlighted social reinforcement as a major cause of CB, as well as communication, a response to the environment and as an expression of emotional states. Wilcox et al (2006) also highlighted a context discourse when interviewing care staff, where CB was seen as an understandable reaction to circumstances and the environment. It was not highlighted as strongly as individual pathology, but it suggests a growth in a broader systemic understanding of CB. This sits more within the social model of disability (Oliver, 1990). Knowing how staff define CB is vital in understanding their responses to it. Many will describe CB as behaviours that are challenging to others and services (Hastings, 1995), yet still hold the view these behaviours are to be changed or are done so intentionally. It has been suggested that staff can be more concerned with behaviour reduction than developing an understanding of what is happening for the person (Hastings, 1995). Hare, Durand, Hendy and Wittkowski (2012) described how staff report considering the whole person and their history as being most relevant to understanding CB.

1.3.2. <u>Topography of Challenging Behaviour</u>

Emerson, Kiernan, Alborz, Reeves, Mason, Swarbrick et al (2001) estimated that between 10-15% of PWLD are labelled as having CB. Campbell (2010) estimates between 5.7% and 20% prevalence in PWLD. This reported wide variance in CB likely reflects differences in understandings in terms of what is labelled as challenging. When considering whether the impact of gender affects whether someone receives a label of CB, Emerson et al (2001) found that 68% of those labelled with CB were male, but Scotti, Evans, Meyer and Walker (1991) found that women were more likely to receive intrusive behavioural interventions. Wilcox et al (2006) found staff understanding of CB was influenced by gender stereotypes, for example, menstrual cycle and character flaws.

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There is some disparity in what care staff view as challenging. Lowe et al (1995) found that inner-directed behaviours, for example withdrawal, social avoidance or stereotypy are often ignored, even though these behaviours may impact on the individual's quality of life. Behaviours that are more outer-directed, such as aggression and destruction of property, are more likely to lead to a referral for specialist support. This is interesting, as it suggests that CB is only attended to when it impacts on those in a position of support. Hastings (1997) highlighted that CB is usually defined by staff as actions that cause organisational problems. Hayden and Stevens (2004), in a study of day centres for PWLD, found 85% of service users displayed some form of CB over the course of a month, the most commonly reported being 'non-compliance'. If a large number of people using a service are constructed as having problematic behaviours, simply because they are not conforming to the routine expected of them, this is suggestive of much wider systemic issues. Hastings (1995) found that staff listed self-injury, aggression and destructive behaviours as challenging, but none listed stereotyped behaviours. Allen (1999) similarly reported that the kind of behaviours that cause the most severe management problems were aggression, wandering away, disturbing noises and temper tantrums.

It could be understood that when a client tries to test the power of the routine, this resistance is seen as troublesome and constructed as CB (Nunkoosing & Haydon-Laurelut, 2012). Within LD settings, resisting the routine is constructed as a problem because staff do not have the authority to ensure compliance with programmes, and so it disrupts the routine of the setting. Wilcox et al (2006) describe how in the case of aggression, staff might be expected to draw on wider cultural discourses about unacceptability of aggression, as well as service specific ones to reassert the balance of power, which may in turn have repercussions for the client.

Much of the research focuses on social CBs, such as aggression. Other behaviours such as stereotypy, may not even be recalled or labelled as CB, despite fitting a formal definition for CB. Hastings (1995) suggested that staff tend to respond more to the topography of behaviour rather than its function,

as there is more focus on the impact on a service as opposed to impact on the individual's quality of life.

1.4. **Historical Context**

It is important to consider how broader understandings of CB, and approaches to it, have changed over time, as this is likely to have an effect on the understanding people working in the field have. Greig (2007) has described how services have historically failed to fully respond to individuals with CB and complex needs. It certainly seems that services have been striving for similar goals and aspirations over the last few decades.

In the early 1960s behavioural approaches first emerged, such as the use of positive punishment to reduce CBs. This was the first time an effective alternative to pharmacological treatments 'managing' CB was considered (Lloyd & Kennedy, 2014; Rhodes, Whatson, Mora, Hansson, Brearley & Dikian, 2011). Prior to this, PWLD and CB were seen as 'untreatable' and were removed from having a role in society, by being placed in institutions away from social support.

In the 1970s the idea of applied behavioural analysis was introduced, and with it the understanding that behaviour could serve operant functions. It was thought that these behaviours were shaped and maintained by positive and/or negative reinforcement (Carr, 1977). This changed the focus from topography of behaviour, to the function that it served. Functions were categorised as *social positive reinforcement*, for example, engaging in preferred activities; *social negative reinforcement*, for example, escape from an aversive environment, and *sensory reinforcement*, for example, touch (Carr, 1977). The approach to identifying variables that maintain CB became known as a functional behaviour assessment. The treatment suggested would be adjusting environmental factors to alter behaviours (Carr, 1977). These ideas have persisted in most services for PWLD.

In the 1980s there was the closure of many long stay hospitals for PWLD and many individuals subsequently moved into community settings. There was a need for intervention models that supported the idea of self-determination within community settings (Rhodes et al, 2011). This was also the time of normalisation becoming a guiding principle in services (Wolfensberger, 1983). Treatment ideas moved to more gentle teaching and with values being promoted around community inclusion and respect. It was starting to become difficult to reconcile the use of aversive methods with these goals. Despite this, there was still a trend towards the use of aversive approaches; 76% of studies published in the 1970s and 1980s were found to use an aversive alone or as part of a combined intervention (Matson & Taras, 1989). Other broader models of intervention were starting to develop in the field, such as family therapy. This considered how people live in family settings and how interactions and relationships within the family might serve to maintain CB. CB could be seen as a symptom of the family's difficulty in negotiating life transitions (Rhodes et al, 2011).

In the 1990s the Human Rights Act (1998) was implemented, which gave the potential to have a large impact on the lives of PWLD, as it made explicit that the rights of PWLD are inseparable from anyone else in society. The right to not be subject to inhumane or degrading treatment (Article 3) and have a right to liberty (Article 5) impacted on the kind of interventions that could be utilised for PWLD and CB. The Mansell report (DoH, 1993) was also first published, which provided guidance, predominantly to commissioners, about how services for PWLD and CB should focus on personalisation and locally provided support.

In the 2000s behavioural interventions evolved into multi-element approaches that took components from cognitive behavioural therapy, mindfulness, solution-focused and narrative models (Rhodes et al, 2011). Valuing People (DoH, 2001) and Valuing People Now (DoH, 2009) were published, focusing on four key principles of rights, choice, independence and inclusion. Valuing People also stated that all public services have a responsibility towards PWLD. In the revised version of the Mansell report (DoH, 2007), it stated that

PWLD and CB are among those most at risk of service breakdown and thus more needed to be done to improve the capacity of services to support these individuals.

The Mental Capacity Act (DoH, 2005) also came into effect, which outlined a person's right to make what others perceive to be unwise decisions, unless they are found to lack capacity, which could impact on how behaviours such as non-compliance are viewed. It stipulated restricted criteria that must be in place in order for restraint to be used. Guidance for a unified approach between health professionals was also published (RCP, et al, 2007).

Behavioural principles continued to be most commonly utilised in services that supported people with CB. The underlying idea being, that the function of the behaviour should be identified and functionally equivalent adaptive skills should be taught (Feldman, Atkinson, Foti-Gervais & Condillac, 2004). Behavioural ideas are sometimes used inconsistently in settings in which people are supported. Without formal behavioural guidelines, staff may use more reactive, controlling and intrusive methods to control CB, in an effort to reduce it quickly, which raises ethical concerns (Feldman et al, 2004). Policy and governmental guidance has made a drive towards creating individualised service responses for people with CB. Services should be based on good knowledge of the person, strong staff/client relationships, staff training being prioritised and a strong management structure, that aims to work towards collaboration (DoH, 2007). The joint guidelines from health professionals similarly spoke of the importance of staff skills and knowledge to create 'capable environments' (RCP, et al, 2007). It is within these environments that complex, multi-element interventions can be implemented. Understandings of CB should move away from concern with an individual and their immediate environment, towards a broader concern with how the wider service is designed (McGill & Mansell, 1995).

Despite values of respect and community involvement underpinning thinking around PWLD at this time, it was sometimes difficult for services to put these values into practice due to resource challenges. Thus a values led approach,

Positive Behaviour Support (PBS) was developed, which aimed towards behaviour change, alongside enhanced community presence, participation and respect. Behaviour change is a side effect of these ideas. PBS was mainly designed for use for PWLD in residential services. It aims to try and understand why, when and how behaviours occur and what function they serve. Allen, James, Evans, Hawkins and Jenkins (2005) described the main tools being multi-component including:

- Proactive strategies-
    - Altering the environment or conditions that increase chance of CB occurring
    - Changing triggers for behaviour, for example, reducing demands, increasing choice
    - Teaching new competencies to staff
    - Use of non-contingent reinforcement
    - Specifying changes in carer behaviour and in service delivery
    - Other proactive interventions include; TEACCH (a focus on routine and structure), Functional Communication Training (supports acquisition of new communicative skills and more control over social environment) and intensive interaction.
- Reactive strategies-
    - Should be the least restrictive and intrusive and be accompanied by a proactive plan, for example, distraction, removing demands.
    - There is an absence of restrictive strategies, such as restraint, if used it must be legally and ethically justified.

PBS aims to train support workers and enhance interactions between staff and PWLD with CB. Staff report PBS training to be helpful, but there is debate about whether it changes how staff understand and respond to CBs, with other factors, such as individual beliefs about CB, having more impact on staff response (Campbell & Hogg, 2008). In a review of interventions utilised for CB, despite PBS having the best evidence base, Allen et al (2005) found it was used infrequently in services. In its place, treatment with no evidence or

negative evidence were being implemented more frequently, such as, anti-psychotic medication and restraint. These issues were actually not very different from the challenges in the 1980s, as discussed. Possible reasons for PBS not being utilised are that the training was not widespread enough, the tools are more labour intensive than aversive methods, and perhaps there was a fear that by putting very structured approaches in place, it moves away from person centred approaches, despite this being at the core of the PBS value base. As more than a decade has passed since this review, it would be interesting to learn how much PBS ideas are integrated into the understandings of CB that support staff have, or if there is something else influencing understandings.

In the current decade, there has needed to be much of the same focus on striving to achieve positive and proactive care. This is particularly in light of the abuse scandal at Winterbourne View which was understood to be caused by a culture of abuse, poor accountability, weakness in the system and inappropriate living settings (DoH, 2012a). A major focus has been on reducing the need for restrictive practices and moving people out of inappropriate inpatient services to community settings, as well as improving regulation and inspection procedures (Bubb, 2015). Part of the Transforming Care agenda (DoH, 2012b) also includes workforce development, which encompasses staff training and considerations about staff wellbeing. The proposed model of care recognises that if the wellbeing of staff is not supported, then there is an increased likelihood of high staff turnover and absenteeism, which disrupts support for the individuals requiring it. The model also raises the issue of societal negative attitudes about PWLD and CB, which need to be challenged as well.

The NICE guidelines for CB (National Institute for Health and Care Excellence, 2015) have also been published, and this has seen a broad range of evidence being used, for example, case studies, which opens avenues for new ideas and thinking to evolve. The National Development Team for Inclusion (2010) has also issued a report about what is a good service model in supporting people with CB. This includes person centred planning and

individualisation, PBS and non-aversive techniques, good clinical leadership, senior management involvement in service delivery, staff recruitment on basis of attitude, less agency staff use and investment in training. This is not significantly different from what has been suggested in preceding decades, which serves to highlight how shifts in service delivery can be slow.

1.5. Understanding the Dynamic Between Staff and Clients

As discussed, the dominant causal and treatment model for CB continues to be behavioural theory. This suggests CBs serve social functions and can be understood using the ABC model of antecedents, behaviours and consequences (Carr, 1977). There is an interactional nature to CB, and staff responses are dependent on their relationships with the people they support (Bromley & Emerson, 1995). Hastings (1997) describes a revised behavioural model that accounts for the actions of care givers that may constitute many of the antecedents and consequences of CB. There is a close relationship between the person's behaviour and the behaviour of staff. Hare, et al, (2012) described how staff might become accustomed and accepting towards CB because of their experience, but they also acknowledged staff might minimise the impact of caring for this client group, due to expectations within services of resilience. Staff may find themselves getting into 'strange loops' where they find they are unable to do the 'right' thing (Oliver, 2004).

Drinkwater (2005) suggested that staff who support PWLD, engage in transforming the person with LD to be assimilated into 'normal' life. When a person is positioned as having CB, the person perceiving it is positioned as having authority to seek intervention to control the behaviour (Nunkoosing & Haydon-Laurelut, 2011). Foucault, (1977) described the discourse of a person with LD as a possessor of an unreliable, docile and leaking body. In the case of CB, perhaps the mind and body are not docile enough (Nunkoosing & Haydon-Laurelut, 2011). In terms of where care workers acquire their understanding of CB, Bradshaw and Goldbart (2013) reported that developing

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a relationship with the client, and direct knowledge of that individual, was valued above all other types of learning.

Understanding the individuals own way of communicating is important in obtaining insight into understanding the behaviour. Due to often having complex physical needs, many individuals may find that using behaviour is their only option to communicate. Carers reported having to guess what clients are communicating, and this may lead to misunderstandings and a resistance from trying to understand on future occasions, due to feelings of inadequacy (Antonsson, Graneheim, Lundstrom & Astrom, 2008).

Distasio (1994) described how clients may be expressing dissatisfaction with the following of routines, such as organised activities that are part of the culture of an organisation. If staff fail to understand this dissatisfaction, then the person may resort to aggression to express it. Even if the staff member does understand, they may not feel empowered enough to make changes to the culture of the organisation, so they may get into a cycle of responding to the behaviour instead. Discourses around power and control can put staff in contradictory positions. Staff are ultimately responsible for the day to day running of the service, which can put them in a position of controlling individuals and the environment. Discourses of self-advocacy and person-centredness, however, can contradict this and influence how staff construct CB. Hastings (1995) described how support staff believe they do at times respond inappropriately to CB in the short term, rather than trying to understand it, due to the their training focusing on managing behaviour.

Buber (2004) described different ways of relating to one another, in particular the I-Thou relation and I-It relation. Antonsson et al (2008) illustrated this by explaining how with an I-Thou relation, staff and clients are aware of each other; they have respect and there exists a relationship of mutuality and reciprocity. In an I-It relation, the staff and clients see each other as isolated qualities that become a relationship of distance and detachment. Both ways of relating might feel helpful and unhelpful to staff at different times.

There has been a small amount of research looking into understandings of CB from the client's perspectives. Griffith, Hutchinson and Hastings (2013) conducted a review and reported clients describe poor attitude of staff, frustration of not being listened to or feeling misunderstood and their own aggressive behaviour as "triggers" to difficult interactions with staff. They also reported a feeling of 'them and us', between the staff and clients. Stevens (2006) found that clients felt staff were both supportive and controlling in response to CB. They also positioned staff as powerful figures who defined what was and was not acceptable behaviour.

1.5.1. The Impact of Staff and Client Defences

Sinason (1992) has spoken about how PWLD are very vulnerable in society and may have had threatening or frightening experiences. As a result, they may develop defences to protect themselves from the pain and anxiety associated with these experiences. She refers to this as 'secondary handicap', which might manifest as self-injury or aggression, and serves to exaggerate the primary disability. Waggett (2012) discussed the relevance of projective identification, whereby individuals defend a fragile sense of their value, placing the more upsetting parts of themselves, for example anger or despair, onto the workers who soak those feelings up. In terms of staff defences, Waggett (2012) described how caring involves being emotionally in touch with all parts of a person, including those parts we find disturbing. He highlighted how with staff working long hours, with low pay, limited supervision and coping with difficult situations, it would be expected to see some defences within both themselves and their organisations. Waggett (2012) referred to defences that enable workers to cope, for example, rotating workers with individuals, which might appear helpful but could be harmful to the care relationship. In Bion's (1961) discussion of group roles, he highlighted how people relate to work situations and pressures in individual ways, and this will impact on how enmeshed they become with the client.

Davenhill (1998) describes ideas from older adults with dementia that could apply to PWLD. If clients do not believe their feelings have been understood

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and responded to satisfactorily, they may respond in aggressive or destructive ways, as their state of mind may be too difficult to tolerate or communicate. Staff can either transform these painful feelings or act them out and experience similar aggressive feelings, which have an impact on the quality of care provided. Support workers are often at the forefront in trying to make sense of complicated communication. Davenhill (1998) states that if there is no space where this countertransference can be processed, a valuable source of information about the client's possible state of mind is lost. This is perhaps where the process of making referrals comes in, as a way of the organisation mirroring the client's difficult feelings. If CLDTs do not understand or respond satisfactorily, staff teams may end up acting out in punitive or destructive ways. Without a reflective space, there is a danger of burn out, high staff turnover and a lessened quality of care, which is very costly for the individuals being supported.

1.5.2. The Impact of Emotions

Contact with people displaying CB often raises strong emotional reactions for staff. Emotions of sadness, anger, fear and disgust are common (Bromley & Emerson, 1995), as well as annoyance and despair (Hastings & Remington, 1995). Fallon (1993) commented that there may be initial feelings of empathy, optimism, curiosity and fear in staff which, over time, can change to frustration, anger, detachment and guilt. Lambrechts, Kuppens and Maes (2009) found staff feelings of fear and anxiety linked to client aggressive and self-injurious behaviour. Hastings (1995) noted that staff appeared to show empathy with clients displaying CBs, and see it as reasonable responses to the conditions they were in.

When clients are not perceived to respond emotionally or socially, this can produce difficult emotional reactions in staff, such as guilt and anxiety (Bradshaw & Goldbart, 2013). The risk here being that without support, staff may view these clients as unable to engage, and in a bid to avoid further negative emotions, they may offer them fewer opportunities to develop skills. Heslop and Macaulay (2009) describe the role of emotion, particularly in

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relation to self-injurious behaviours, which they found care givers believed was used in response to difficult emotions and circumstances, such as abuse and bereavement. Behavioural models of CB would suggest that care givers respond to behaviour to avoid feeling negative emotions. Unpleasant emotions can lead to staff avoiding or taking quick yet ineffective action, for example, providing attention that might reinforce behaviour in the longer term. Whittington and Burns (2005) noted a number of responses used by staff to cope with difficult feelings, which included shutting out or avoiding the client but, conversely, also getting to know the client better. They suggest that dilemmas faced by staff be made explicit and resolved through integrative models of training. Staff should spend more time enhancing staff/client relationships and have space to acknowledge the emotional impact of the work. Methods of supporting staff to cope with emotional reactions to CBs are vital, especially if the intervention used might lead to an escalation of behaviours in the short term (Hastings, 1995).

1.5.3. <u>The Impact of Stress and Burnout</u>

It is interesting to consider burnout in the context of understandings of CB. Staff can sometimes spend a lot of time and resources trying to mentalise what is going on for a person, which can put a lot of pressure on them. Other psychological processes, such as splitting, with staff viewing clients in extremes of good or bad (Carser, 1979), may also impact on burnout. Disparate views may be formed of an individual's behaviour, across staff members, which can make it difficult to work in a consistent way. Maslach, Schaufeli and Leiter (2001) conceptualise burnout out as feelings of emotional exhaustion, a tendency to depersonalise the person being supported and diminished feelings of personal accomplishment. Lundstrom, Granheim, Eisemnan, Richter and Astrom (2005) found that 40% of carers accepted violence as a natural part of daily care, which will inevitably impact on how they understand it. They found that 30% were in the 'danger zone' for burnout.

Bromley and Emerson (1995) reported that the biggest source of stress associated with supporting someone with CB, centred on difficulty in

understanding the behaviour, unpredictability of behaviour and when there is an absence of a way forward. When considering the views of support staff, Campbell (2007) reported that the understanding of CB impacts on the kind of therapeutic intervention used, how effective those inventions are and whether a behaviour is maintained through behavioural mechanisms. Staff working with people with CB reported being significantly more anxious than staff who work with PWLD and no CB. They also feel less supported, were less clear about risk and had lower job satisfaction (Jenkins, Rose & Lovell, 1997).

Mills and Rose (2011) found a relationship between CB and burnout in support staff, which is mediated by negative emotion, in particular fear of assault. Staff may be at higher risk of emotional burnout if they do not have emotional support, if they self-blame or disengage from the task (Hastings & Brown, 2002). Staff are best able to manage the emotional impact of the work, by employing strategies such as positive re-framing, humour and making use of emotional support (Hastings & Brown, 2002). It has also been found that staff can develop an 'emotional immunity' to CB, as they gain more experience (Hastings & Remington, 1995), that could lead to emotional distancing from clients and a higher likelihood of burnout.

1.6. Attribution Theory and Challenging Behaviour

Much of the research in the field of CB looks explicitly at, or makes reference to, attribution theory (Heider, 1958). The behaviour of support staff is determined by their emotional responses and beliefs and attributions about CB, and the people they support (Hastings & Remington, 1995). Bromley and Emerson (1995) suggest that staff attributions about the causes of CB, affects their responses and consequently the quality of life of PWLD. Attribution theory assumes that when people perceive an event, they try and understand a cause or attribute responsibility, along the dimensions of locus, stability and controllability (Heider, 1958). This is relevant to the understanding of CB, as staff inevitably make attributions about the behaviour of individuals they support.

Locus refers to whether the cause of a behaviour is perceived as internal or external to an individual. Studies have shown that staff may attribute CB to internal and controllable causes within LD settings (Cottle, Kuipers, Murphy & Oakes, 1995; Dagnan, Trower & Smith, 1998; Sharrock, Day, Qazi, & Brewin, 1990). When a 'fundamental attribution error' is made, which is when behaviour is attributed to internal and ongoing states, rather than acknowledging the influence of the environment (Heider, 1958), staff may be less likely to offer helping behaviours to the person. This suggests these attributions are not helpful for the individual (Dagnan et al, 1998). *Stability* refers to whether the cause is described as transient or long term. Totsika, Toogood, Hastings and Lewis' (2008) longitudinal study found that 79% of a sample of PWLD still presented with serious CB, eleven years after first identified, and thus concluded it is persistent over time. *Controllability* refers to whether the person is deemed to have control over their behaviour. The idea that CBs are intentional, relates to the belief that such behaviours are used to achieve something in particular, and thus the view that clients 'know what they are doing' (Hastings, 1995). This may result in individuals being blamed for their actions and could lead to models of punishment being utilised to stop behaviours occurring. Weiner (1993) distinguishes between controllability and responsibility. Controllability is the degree of control a person has over a cause of behaviour, whereas responsibility is a judgement as to the degree a person can be blamed for this cause.

Sharrock et al (1990) found that staff who attributed causes of CB as being unstable, external and uncontrollable, were more willing to help clients with CB. Poppes, van der Putten, ten Brug and Vlaskemp (2016) found that support staff report the biomedical model as the most plausible explanation for CB in people with severe LD. This is possibly because this group of individuals are seen as having less control over their behaviour, and thus staff may see the CB as unchangeable and 'belonging' to the individual. Therefore, they are less likely to consider other factors that might be influencing it.

Dagnan and Cairns, (2005) describe different models of understanding behaviour. The 'moral' model is when a person is judged as responsible for the development of a behaviour and responsible for the resolution. Intervention would involve encouraging self-motivation. The 'enlightenment' model is when the person is seen as having responsibility for development of the behaviour, but not for its resolution. This is associated with punitive interventions. The 'compensatory' model suggests people are not responsible for the development of the behaviour but they are for the solutions. Interventions involve offering the person resources so that they can implement change. Finally the 'medical' model is when the person is neither responsible for development or resolution of the behaviour. This is a passive view that leads to more of a paternalistic intervention. As these different understandings of cause might lead to different interventions, there may be uncertainty or disagreement from staff in how to respond (Whittington & Burns, 2005).

In some studies staff have displayed contradictory beliefs, for example, understanding a behaviour as socially or environmentally maintained but delivering reactive interventions, such as stimulation or attention, which could increase occurrence of the behaviour in the long term (Hastings, Remington & Hooper, 1995). Whittington and Burns (2005) described the dilemmas that care staff can experience when trying to understand CB. This can include ambivalence about whether to see behaviour as 'learned', and responding 'firmly' (which is seen as ignoring communication needs), or to see behaviour as 'communication', and responding 'kindly' (which is seen as reinforcing the behaviour). Whittington and Burns (2005) also found a desire to maintain values of kindness and respect, possibly due to values based discourses of normalisation and social role valorisation promoted within services (Wolfensberger, 1983). These discourses can seem to pull staff in conflicting directions.

It has been suggested that some attributions may lead to inconsistent care or reinforce CB (Dunne, 1994), which inevitably would have an impact on the individuals' quality of life.

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1.6.1. <u>Attribution Theory and the Role of Emotions</u>

Given the common emotional reactions that staff may have in response to working with CB, it is interesting to consider the interaction between emotions and attributions. Attribution theory has been further developed by Weiner (1980, 1985, 1986), who asserted that the model had applicability to situations where understanding of behaviour is an issue. The theory explains how the emotions and cognitions that carers experience about causes of CB, can impact on the helping behaviour and responses they give to the people they work with.

Weiner (1986) highlighted the importance of emotions as a mediator in determining the helping behaviour of staff. There is a suggestion that negative emotions are a vital mediating factor between attribution and behaviour in staff working with people who present with CB (Dagnan et al, 1998; Wanless & Jahoda, 2002). In particular anger and sympathy are suggested to determine the likelihood of help being offered (Weiner, 2000). Sympathy was found to be the single biggest predictor of helping behaviour, which was predicted by how responsible the individual was seen as being for their behaviour (Dagnan & Cairns, 2005). If CB is perceived as intentional, under the personal control of an individual and stable, it will cause more negative emotions in staff and result in less helping behaviour (Hastings, Reed & Watts, 1997). The attribution of CB being permanent was linked to feelings of confidence, which seems to contradict Weiner's attribution theory, with Weiner's model failing to capture the dynamic element of the interaction between staff and clients (Wanless and Jahoda, 2002)

Buunk and Schaufeli (1993) have discussed the relationship between client and care giver, and how a seeming lack of reciprocity can drain emotional resources leading to high expressed emotion. This can result in a deterioration of the supporting relationship, and in an attempt to rebalance emotional resources, staff may use post-hoc reasoning to make more

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negative and internal attributions about the behaviour, to justify why they had withdrawn helping behaviour.

It is interesting to consider why there is such a significant research base focusing on attribution theory and CB, when the most commonly used interventions currently make use of behavioural theory, such as PBS. Attribution theory only explains why judgements might arise. It raises the question as to whether attitudinal influences supersede behavioural ideas in practice. For example, someone might have an individualised PBS plan in place, but if the member of staff judges a certain behaviour to be internal or controllable on a certain day, this may override intentions to respond according to the plan. Thus it is important to look to the attributions and feelings staff have.

1.7.   **The Referral Process and Interaction Between Referrers and Responders**

With the closure of institutions for PWLD, health professionals were no longer in direct working contact with these individuals. Teams had to adjust to making their services available to people living in community settings, so different dynamics were created between staff working with PWLD.

1.7.1.   The Referral Form

Drinkwater (2005) spoke of how systems of power work within residential settings; any resistance to the goals of the service are discoursed as CB, and if any power is displayed by a person with LD, it is problematised. Nunkoosing and Haydon-Laurelut (2011) describe the community life of PWLD, involving constant surveillance, an unchanging rigid routine and mortification of the self, which is the distance created between staff and clients.

The way referral forms are written in general are often problem-saturated (White & Epston, 1990) and made on behalf of PWLD. Nunkoosing and Haydon-Laurelut (2011) found that referrals were often made to the CLDT

when the person's behaviour conflicted with the routine of the staff. The authors highlighted an absence of person-centred discourses. The systems of power exist beyond the residential setting, with the CLDT having the power to decide who does and does not receive the specialist input. When referrals are made to the CLDT, people are often positioned as the problem to be solved and in need of surveillance, and the perceiver is seen as having the authority to seek intervention to control the person and their behaviour (Nunkoosing & Haydon-Laurelut, 2011).

It is interesting to explore the interaction between the referrers and those who respond at the CLDT, in regards to the referral process, as it enables us to see how understandings are constructed. It also helps us to explore, not only the discourses about the people who are served, but what discourses might be generated about the services with whom they are professionally linked. Support staff are positioned in a way whereby they have to provide the CLDT with enough information for a decision to be made on how to support them best. There is an attempt by support workers to highlight to professionals the difficulties of the work they do, and making a referral makes this explicit (Nunkoosing & Haydon-Laurelut, 2011). They found that referrals are often made simply to confirm decisions that have already been made, acting more as a legal safeguard. It was also noticeable in this research that it was often managers who made referrals and thus controlled the image of the service. The voice of direct support staff and the client, and consideration of how they might construct the 'problem', was absent. Goffman (1961) spoke of the 'inmate' who would be excluded from knowledge about decisions regarding their fate; staff making referrals creates distance from the people they support. If staff could understand how they have been positioned by these discourses, it could shift the emphasis away from changing people, to changing the systems that disable people.

1.7.2. Barriers and Solutions to Communication Difficulties

Given the differences between teams, there are inevitably communication breakdowns between referrers and responders, for example, not

implementing guidelines, not asking for help or making assumptions based on prior experience (from both referrers and responders). Staff may be reluctant to call in for help from the CLDT for a number of reasons, including not knowing how to use the referral system, feeling as though they have failed, not wanting outsiders to intervene with practices already in place or fear that the 'expert' may focus more on organisational and managerial issues and less on the levels of CB (Jenkins, et al, 1997). Haydon-Laurelut, Nunkoosing and Millett (2014) found that whilst service users are under the surveillance of support teams, the support teams can feel under surveillance themselves from the scrutiny of CLDTs. The ability of the clinical staff to empower others stems from their possession of power in the first case, which implies they have the ability to transfer power. This continues the culture whereby power is kept away from the client (Bailey, Hare, Hatton & Limb, 2006).

Support staff beliefs and feelings about CB are influential and have been found to sometimes override pressures to follow behavioural interventions set up by outside professionals (Hastings & Remington, 1995; Bromley & Emerson, 1995). McKenzie, McLean, Megson and Reid (2005) found that potential barriers to implementing guidelines from the CLDT might be practical difficulties, such as time, or seeing guidelines as irrelevant and not fitting the problem. Whitworth, Harris and Jones (1999) found that staff preferred following their own informal rules around safety, rather than following more formal guidance of outside professional interventions. Hastings (1995) found that new staff learn their understandings of CB from the existing staff's behaviour, and they may be assimilated into the organisational culture before receiving any formal training. He also found that informal agreements on how to work with CB may achieve the same status as formal interventions, and in this case formal interventions from external professionals are seen as unnecessary complications, presumed not to work anyway. Lowe et al (1995) highlighted how distinctions need to be made between 'coping' with an individual and 'serving their needs' to achieve the best outcome for their quality of life. This enables external professionals to plan preventative instead of reactive strategies. For an intervention from the CLDT to be successful for referrers, there needs to be a collaboration of the natural environment,

commitment to the individual with CB, and a willingness to adopt strategies suggested by specialist clinical staff (Lowe & Felce, 1994).

The observed differences between support services and specialist services can serve as a barrier to successful interventions. The support staff interviewed by Whitworth et al (1999), refer to specialist professionals as 'outsiders' and describe a 'them and us' culture. This is reflective of Griffith et al's (2013) reports of clients noticing a 'them and us' feeling with carers, which suggests it might be a feeling shared across the network. There was a sense that external input led to negative feedback and not feeling valued (Whitworth et al, 1999). External professionals should have more input into the day to day operation of support services, to overcome the culture of mistrust and to provide more support for staff in delivering interventions, so that there is a sense of a 'common cause' when supporting people with CB.

Structures within support services can reflect the organisation culture, as described by Schein (1996). The CPs, psychiatrists and multi-disciplinary team are the 'engineers' directing from a distance, and the direct support staff are the 'operators' who feel distrustful of the engineers involvement. This would suggest there needs to be greater understanding of the interplay between those suggesting the interventions and those delivering them. If their understandings of CB are significantly different to one another, this could play out in unhelpful ways.

Carnaby, Roberts, Lang and Nielsen (2011) described how support agencies did not value having health professionals advising from a distance. They preferred having clinical staff working alongside them and so trialled a 'flexible response service' based on this idea. This model lessened the professional distance between those who provide care support and those offering specialist support, as the health professionals were delivering care support as well. This may not be seen as cost effective to use clinical staff in this way but the benefits of support staff working alongside clinical staff allows for a greater level of modelling, reflecting and empowering, to develop dynamic approaches.

The Mansell report (DoH, 2007) discusses how we cannot expect support services to have all of the necessary skills to deal effectively with CB. CLDT's should be aware that support services may struggle to put strategies and ideas into practice, but, additionally, support services need to be open minded to altering their practice. If services understand the differences between them, it may lessen the frustrations that can be expressed when ideas are not implemented. Hastings (1997) suggests that given the complexity of the behaviour that people may display, services should not be relying on generic labels such as CB. He suggests specialist services should regularly request information about specific types of behaviours instead. This way of viewing CB acknowledges there may be patterns and systemic issues that impact on the prevalence of certain behaviours at different times, and is perhaps less individualising.

1.7.3. <u>Maintaining a Systems Approach</u>

Using a systemic approach allows support staff to take a step back from the complexities of working with a person with CB, in order to reflect upon interactions and behaviours that might prevent behavioural interventions being successful (Rhodes et al, 2011). Allen (1999) spoke about the importance of a systems approach, when supporting people with CB, which considers all salient personal, inter-personal and organisational variables. Jenkins and Parry (2006) looked at how bringing together a network that may be out of synchrony can be useful when a system is in a state of 'stuckness'. This way of working moves away from problems being located within the individual, and it acknowledges how support systems can be crucial in maintaining or alleviating difficulties.

Haydon-Laurelut and Nunkoosing (2010) describe how systemic theory can be used to invite referrers and the referred to join together, to understand their relationships more fully. The person with LD, who is historically excluded from the production of knowledge, can be involved in the thinking about the meaning of the referral. Maintaining a systemic approach is recommended within LD services, as it is important to avoid creating closed impermeable

systems, due to the often large networks and connections PWLD have in their lives (Baum & Lynggaard, 2006). One way of doing this is introducing new information into a system to foster new ways of thinking. Referrals that are made and received should be approached in a curious way to broaden the understanding of different perspectives. When any referral is made to a CLDT, the team and clinicians will have multiple ideas and assumptions about why that referral has been made. This can limit the team's ability to hypothesise about the referral. Similarly, referrers can have many ideas about how a referral will be received, given past experience or perhaps assumptions made about the behaviour. Although the work carried out by the CLDT focuses on changing the behaviour, it must also focus on changing systems, relationships and organisations. It is essential that teams are able to understand the perspective of one another in order to develop their understanding of CB.

1.8.   **Clinical Relevance and Rationale**

There is a mutual dependence between CLDTs and support services, but it is possible that both have different ideas about the difficulty they are facing and the support that is needed. This is where my curiosity for the study arose. As discussed at the start of this section, CB is not an objective concept, it is socially constructed, so we need to consider who are we serving and whether accepted concepts of CB actually serve wider organisations rather than the individuals. Nunkoosing and Haydon-Laurelut (2011) make reference to 'referral careers' of individuals. They question whether the re-referral of people to the CLDT serves the person or maintains the continuation of the home and CLDT. It is interesting to consider how this interaction between support services and the CLDT exists. Ferguson (1994) spoke about how the label 'incurables' justified the long stay institutions existence in society. Given how society has changed, as well as beliefs about PWLD, it is thought-provoking to consider whether CB justifies the existence of clinical psychology involvement in CLDTs. If we did not use CB as a concept, would that relationship exist in such a way that it does currently? As discussed, it is

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important to maintain open minded and curious systems in this field of work. This research could make explicit some of the referrers and responders ideas and assumptions, and this may enable or disable teams to respond in a consistently systemic way.

In terms of adding to the research base that already exists, Haydon-Laurelut et al (2014) recommended that further research be conducted from the referrer's perspective, about understandings of CB, including more diverse support agencies. Nunkoosing and Haydon-Laurelut (2011) discuss the need for further research with paid care staff who make referrals to CLDTs, to consider how CB is talked about within this dynamic. The majority of research into staff understandings has been from residential staff perspective. Looking to different contexts, such as day services, as in the presenting study, is important to understand constructions of CB through a different lens. Haydon-Laurelut et al (2014) also comment that there is a need to hear the CLDT perspective about their responses to referrals. Much of the research into the CLDT perspective has looked to overall team values and culture (Slevin, McConkey, Truesdale-Kennedy, Barr & Taggart, 2007). There is a lack of research looking to how healthcare professionals from the CLDT perspective understand CB. Also, there has been no research to date that has looked simultaneously at perspectives from referrers and responders. Given this, there appears to be a good rationale for this study.

1.9. **Research Question**

How is CB constructed by referrers and clinical psychologists in people with LD?

2. METHODOLOGY

This chapter will describe the chosen methodology for this study. It will start by stating the epistemological position and gives a rationale for why a qualitative approach was taken and specifically why Thematic Analysis (TA) was used. Following this, I will reflect on the role I had as the researcher. I will then describe the procedure of the study, with information on the recruitment methods, the sample, ethical issues and data collection. It will conclude with details about how the TA analysis was conducted.

2.1. Epistemological Position

A critical realist epistemological stance was taken to explore individual participant's understandings of CB. This stance sits between realist assumptions that accept there is a reality we can observe, and social constructionist or relativist ideas, where there are perceived to be many versions of reality (Harper, 2012). Critical realism aims to get an understanding of what is 'really' going on in the world, yet acknowledges that the data gathered might not provide direct access to this reality (Willig, 2013). It acknowledges there is a 'real world', but the researcher can only access a subjective and socially influenced part of it (Braun & Clarke, 2013).

The way in which CB is understood and spoken about is socially constructed within a broader historical, cultural and social context, and it acknowledges a multiplicity of views. Instead of aiming to find a 'truth' about CB, I have gained access to several different stories about how CB is understood, acknowledging my own influence on this as well. There is a material reality in the way that services and organisations are set up for people with CB, and the consequence for the individual, who receives a label of CB, is assumed to be a real experience. However, directly observed contact with this reality cannot be achieved, as many people with LD are not aware they have been given a label of CB, yet the responses of others to the label are felt in a way that is real. This study accesses only the culturally and socially determined perspective of individuals who support

those with a label of CB. The meaning will be constructed by the participants and through my lens as a researcher. A reflexive stance was taken throughout the research process (section 2.4).

2.2. Qualitative Design

This study uses a qualitative research design enabling the production of rich, descriptive data. A qualitative approach aims to capture patterns of meaning, and it acknowledges these can only be understood within the contexts that they arose (Braun & Clarke, 2013). There has been a paucity of research into the perspectives of professionals who respond to referrals for CB, in the context of LD, and there is a need for further research on the perspectives of referrers who make the referrals to CLDTs. Existing literature has suggested the relationship between the CLDTs and referrers impacts on how CB is understood, for example, organisational issues, feelings of being scrutinised as well as institutional discourses of LD (Nunkoosing & Haydon-Laurelut, 2011; Haydon-Laurelut, et al, 2014). A quantitative method would not have allowed for an exploration of the different perspectives of CB, with a consideration of the complex relationship between the different contexts people are within.

2.3. Thematic Analysis

Braun and Clarke (2006) discuss the importance of matching research aims with the theoretical framework and method. This study made use of a TA approach to method. TA is a method for identifying and analysing patterns of meaning in qualitative data (Braun & Clarke, 2013), whilst keeping in mind the limits of what can be observed from a critical realist position (Willig, 2013). TA is described as the most systematic and transparent type of qualitative analysis, as it looks for prevalence of themes, without sacrificing depth of analysis (Joffe, 2012). Thematic patterns can be directly observed at the manifest level or interpreted at the latent level (Boyatzis, 1998).

When considering which qualitative method would be most appropriate for this project, Interpretative Phenomenological Analysis (IPA) and Grounded Theory

(GT) were initially considered as well as TA. IPA aims to develop in-depth understanding about individual's lived experience and meaning attributed to this (Smith & Osborn, 2008). GT is an inductive approach whereby the aim is to construct a theory grounded within the data (Charmaz, 2013). TA differs from IPA and GT, as it is a method that can be applied across a range of theoretical and epistemological approaches (Braun & Clarke, 2013). This appealed to me, as it gave the opportunity to consider the varied experiences of the participants, looking at both the semantic and latent features of the data. The study was exploratory in nature, rather than trying to explain practices with the development of theory (GT) or focusing just on experiential features of the participants' experience of CB (IPA), hence why TA was the chosen method.

Inductive analysis is driven by the data without trying to fit it within an existing framework, whereas deductive analysis is more theory driven (Braun and Clarke, 2006). Due to the exploratory nature of this study, the analysis was primarily inductive with the themes remaining close to the data, to allow the generation of themes independent of any prior knowledge or theory. Making use of deductive analysis as well, allowed me to acknowledge how my experience and existing knowledge influenced the questions I asked and how I interpreted the data. It is not possible to avoid any influence of theoretical knowledge, for example from the literature review or prior experience. Using both an inductive and deductive approach allows for generation of new findings, as well as being aware of previous research findings being repeated (Joffe, 2012).

2.4. Researcher Reflexivity

Retaining a reflexive stance throughout the research was essential in maintaining the data quality and transparency. As a researcher, my experience of the world is influenced by my assumptions, intentions and actions, and these factors might impact on the research process from initial ideas to writing up (Yardley, 2000). The different insider and outsider positions that I held were considered (Le Gallais, 2008). I was able to take an insider position in both groups of participants, referrers and CPs. From a referrer perspective I have experience as a support worker for PWLD in two settings (a college and a day service), and

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from a CP perspective I have worked as an assistant psychologist for three years in an LD team and for six months, as a trainee CP. I also have the position of 'outsider', as someone who is training to be a CP, so I am not currently inside the referrer role and not yet inside the qualified CP role. This is explored further within the discussion.

Throughout the process I paid attention to where any researcher biases might arise and how they might impact on the research process (Thompson & Chambers, 2012). It is not possible to be a neutral researcher as I have my own understanding of CB. I understand CB to be a socially constructed concept that does not describe something concrete and observable. I was aware of how my perspective could influence how I ask the questions and the prompts used, for example, the risk of not following up ideas when there is assumed shared understanding. I kept reflective notes throughout the research process. This enabled me to bracket off any assumptions and ideas that I had, and to revisit them through the analysis process.

2.5. Recruitment and Sample

2.5.1. Recruitment
Participants were recruited from five inner London NHS Trusts and three London boroughs. It was felt to be important to recruit a broad range of professionals working in LD services, so that perspectives from different services could be heard.

2.5.1.1. Clinical psychologists: I attended a NHS LD special interest group, covering a particular region of London, where I presented a brief outline of the study. The group agreed that I could recruit via their email list. Following the meeting, I composed an email (Appendix A) and attached the information sheet (Appendix B), which was cascaded to all the members. Potential participants were invited to contact me directly if interested in taking part. The six recruited CPs, from five different London NHS Trusts, made contact and interview dates were arranged via email. As specific Trusts were not targeted during the recruitment process, and contact was made outside of NHS streams of

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communication, Trust research and development approval was not deemed necessary.

2.5.1.2. Referrers: I had two field contacts from two NHS Trusts that covered five boroughs of London. They shared the contact details for all of the council funded day services in those boroughs. I directly contacted all the managers of these services via email (Appendix C). I requested to attend a staff meeting to discuss further with the whole team, if there was interest. Four day services responded from three boroughs, and I attended their team meetings to explain the study. Six potential participants volunteered to take part at the meetings and they were left a copy of the information sheet to consider outside of the meeting. I contacted them via email, to review their decision and interview dates with all six were agreed. As the participants were recruited by direct contact with the team managers (through field contacts), council research and development approval was not deemed necessary.

2.5.2. Inclusion and Exclusion Criteria

2.5.2.1. Clinical psychologists: Any CP working in a CLDT, who had been involved in responding to at least one referral for support regarding CB in the last year, was eligible for inclusion in this study. 'Respond' was specified as having met with the person and/or their network for an assessment and/or intervention.

2.5.2.2. Referrers: Any support staff working within day services for adults with LD, who had been involved in making at least one referral to the CLDT for support regarding CB in the last year, were eligible for inclusion in this study. It was acknowledged that individuals might flag up the need for the referral, but not actually be the one who makes the referral, due to the way in which organisational systems work, however, they would still be eligible for inclusion. This was important, as previous research has focused more on management, and I was keen to recruit participants from a range of roles, to enable different voices to be heard.

A further criteria for eligibility was that the response to the referral was partially or totally complete. This was in place to ensure that only participants who had

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experience of interventions or support regarding CB could take part, so that they had 'live' examples to refer to in the interviews.

2.5.3. The Sample

Six CPs and six support workers (SWs) volunteered to take part in the study. Their pseudonyms, years of experience are outlined in table 1.

Name *	Years of experience in the field of LD and CB
Referrers	
Charlie	2
Tony	20
Alex	25
Sam	20
Jamie	19
Ash	25
Responders	
Kim	14
Sandra	10
Annabel	8
Sandy	12.5
Rachel	9
Jay	22

Table 1. Sample description

* Random pseudonyms were assigned to each participant.

Looking at the recruited sample as a whole (both referrers and responders), it was notable that there was a large range of years of experience worked in the field of LD and CB, with a range of 2-25 years. In the CP group there was a mean of 12.5 years' experience, and in the referrer group there was a mean of 18.5 years' experience. The CP group had five females and one male participant. The referrer group had five males and one female participant. There was a diverse spread of ethnic background, which was similarly matched across both groups.

Guest, Bunce and Johnson (2006) estimate that data saturation is achieved at approximately 12 interviews, but the basic elements for main themes may occur at six interviews. As there were two groups of participants being interviewed, an aim for a total of 12 interviews was considered. The minimum recommended for small projects is six (Braun & Clarke, 2013), this enabled me to gather an appropriate amount of data from two groups, without being overwhelmed with the amount of data at analysis.

2.6. Ethical Issues

Potential ethical issues that could arise were considered as outlined in the British Psychological Society's (BPS's) code of human research ethics (BPS, 2014).

2.6.1. Ethical Approval

The University of East London Research Ethics Committee provided ethical approval for the study (Appendix D) and no amendments were requested.

2.6.2. Informed Consent

Before the interview commenced, participants were given the opportunity to re-read the information sheet, and to ask any questions before being asked to sign the consent form (Appendix E). The consent form outlined that they were free to withdraw from the study at any time, without disadvantage to themselves.

2.6.3. Confidentiality

Demographic information and interview data was kept confidentially. Participants were informed confidentiality would only be breached if there were concerns for the participant or another person's safety, which would ideally be discussed with the participant before doing so. This would be discussed with my research supervisor. There was no need to break confidentiality during this study.

Participants were asked to refrain from using identifiable information in the interview and to use pseudonyms where possible. They were also informed that any identifiable information that was given would be altered at the point of transcription. The audio files were deleted from the audio recorder after being

uploaded. The audio files and transcripts were saved on a password protected laptop and password protected USB. These recordings will be deleted following examination of the thesis. The written transcripts will be kept on a password protected USB file for five years, for potential use in any publications written by myself. Consent forms, initial questions and printed transcripts were kept in a locked environment that would only be accessed by the researcher and, on request, the supervisor and examiners.

2.7. Interview Process

2.7.1. Materials

2.7.1.1. Digital audio recorder: All interviews were recorded using a digital audio recorder (Sony ICD-PX333). Participants were informed in the interview sheet that the interview would be recorded. They were verbally reminded of this before the interview.

2.7.1.2. Interview schedule: This was constructed prior to the recruitment process, following the literature review and in discussion with my supervisor and field supervisor (a CP with experience in the research area). Two versions of the schedule were created for the referrer and CP interviews (Appendix F). Participants were asked the same basic number of questions, and each question mapped onto an equivalent question in both schedules. This was so that both groups had the opportunity to cover similar areas. Inspiration was sought for the questions from Haydon-Laurelut et al's (2014) study. One of their aims was to understand the processes that created discourses around LD and CB, and some of their interview topics fitted with my own aims. The questions were asked in a flexible way whereby participants were encouraged to follow up pertinent points when relevant.

Two pilot interviews were conducted to enable me to consider how appropriate the questions were for the target audience. The data was not used for analysis, but ethical issues were considered in the same way as for the participants. The first pilot was conducted with a manager of a day service for PWLD, who has made many referrals for CB, and was therefore in a position to comment on

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appropriateness of questions. Some recommendations arose from this, including removing a question that asked the participants to consider how the CLDT understand CB. It was pointed out how difficult it is to consider this, as there are so many different views. It was decided that although I was attempting to generate whether there was a broad understanding of how CLDTs understand CB, it would be difficult to give one answer and could be perceived as there being a 'right or wrong' answer. This question was removed. There was also a question that asked how the CLDT may have felt when reading the referral, which again, it was stated, was impossible to know. I decided to keep this question in. It was felt that although this information could not be gathered in a 'true' sense, it encouraged the participant to mentalise the feelings of the 'responder', which may have impacted on their own constructions of CB, and so was relevant to the research question. The second pilot interview was conducted with a CP, working in a CLDT, who has received and delivered numerous interventions for CB referrals. Ideas were put forward about potential prompts that could be used in order to access further reflections, for example, prompting participants to consider whether a specific piece of work impacted on their understanding of CB. All data was destroyed, following the feedback, and the interview schedule was amended with the changes as discussed.

2.7.2. Data Collection

Interviews were held at the participant's place of employment. Interviews ranged between 34-59 minutes in length. Following the signing of the consent form, participants were then asked to fill out an 'initial questions' questionnaire that covered some demographic, experience and training based questions (Appendix G). At the start of the interview it was also highlighted that I would use the term CB throughout the interview, as it is most commonly used within services at present. It was, however, acknowledged that there may be multiple ways of understanding it, which the interview would explore. The participants were then asked each of the questions in the schedule (Appendix F). The way in which the questions were asked, varied depending on the flow of the interview, with prompts and follow ups used when necessary. This enabled me to minimise the impact of any personal biases using the planned questions and prompts, but not feeling too constrained to follow up points when clarity was required or additional

information was needed. At the end of the interview participants were given the opportunity to reflect upon the process and ask any questions.

2.8. Data Analysis

2.8.1. Transcription of Data

Transcription is the first stage in data analysis, as it enables the researcher to start to become familiar with the data (Braun & Clarke, 2013). The audio recordings of all interviews were transcribed at a semantic level by the researcher. The focus was placed on the words that were said, rather than how it was said (e.g. tone, emphasis). This type of transcription is referred to as 'Jefferson Lite' by Potter and Heburn (2005). It notes some of the grosser linguistic elements, for example pauses and laughter, but not further detail. For TA it is often not deemed necessary to have all paralinguistic features, such as coughs and tone of voice included, as it is in other types of qualitative analysis, such as conversation analysis (Braun and Clarke, 2013). The transcription conventions used were based on Braun and Clarke's (2013) notation system and adapted for this study (Appendix H). All identifiable information was removed as it was transcribed, and it was substituted with an equivalent replacement word. Each audio file was listened to in full alongside the full transcripts, to check for errors.

2.8.2. Thematic Analysis Process

The analysis followed the six stages of TA as outlined by Braun and Clarke (2006):

 Phase One: Familiarisation with the data

At this stage it was important to become immersed in the data following transcription. The completed transcriptions were read and notes of initial analytic observations were made using hand written annotations in the margins.

 Phase Two: Coding

After familiarisation, labels were generated for the important features of the data, which were relevant to the research question. Each transcript was worked through in this way systematically. This process aimed to capture both a sematic and conceptual understanding of the data. Every data item was coded using

notes in the margin, so that as much information as possible was captured (see appendices I & J for examples of annotated transcripts). As this research was focused on how CB is understood, this remained the focus of the analysis. The codes were clustered into groups to aid the identification of relationships and themes.

Phase Three: Searching for themes

A theme is a coherent and meaningful pattern in the data that is relevant to the research question. This phase involved looking for similarity in the coded data, making connections and forming broader codes. This was an active process whereby I constructed the themes; they were not simply discovered. Relationships between codes, sub-themes and higher order themes were considered.

Phase Four: Reviewing themes

This phase involved checking that the themes fit alongside the coded extracts and the full transcripts, and asking whether the themes tell a convincing story about the data collected. There were two levels to this:

Level one- Checking the themes against the data, to ensure the themes were supported by relevant data, and to check for coherence and distinction. Themes that were not distinctive enough or had a small amount of data attached to them, were collapsed into broader themes or split when too broad. A thematic map was created (Braun & Clarke, 2006) that is illustrated in the analysis section.

Level two- Themes were then checked by re-reading all of the data set from the transcriptions. This enabled missing data to be identified, and to ensure the thematic map fitted coherently.

Phase Five: Defining and naming themes

The themes were analysed to consider the information they conveyed, and to consider how each theme fitted into the overall story about the data. Names were given to each theme.

Phase Six: Writing up

This involved weaving together the analysis and data extracts, in order to tell a coherent and persuasive story about the data, and contextualising it within existing literature.

3. ANALYSIS

Following the interviews with the six CPs and six support workers, the recordings were transcribed and the data was then analysed. The two groups were coded and analysed separately, so that any differences between the groups could be considered. This chapter will examine the overarching themes and subthemes that emerged from the data, with context provided using quotes from transcripts.

Although brief interjections, single repetitions and connecting words were transcribed, they were not analysed in detail and have thus been removed from the quotes presented, to improve readability. Words removed from quotes to reduce length are indicated by "…". Text added to assist any clarification is indicated by square brackets [text]. For clarity, extracts used will state whether the participant is a clinical psychologist (CP) or a referrer/support worker (SW).

3.1. Summary of Themes

Despite the data being analysed separately according to group, the same six overarching themes emerged for both the CP and referrer groups, with mostly similar subthemes underpinning them (see appendices K-O for code and theme development). The theme of 'interventions' was present throughout most of the interviews, with discussions of different interventions used (proactive vs reactive), resource challenges and outcomes. As the research question was looking at understandings of CB, I decided that this theme would have told us more about the consequence of understandings, rather than the understanding itself. Therefore it was decided 'interventions' would not be included in the analysis and instead the focus was on the five remaining themes. Given the fact the overarching themes were largely overlapping across the groups, it felt logical to present the analysis together, so direct comparisons could be made throughout. The final five themes are displayed visually in figure 1 and in appendix O. For the purposes of this analysis, I will focus on the three central themes, acknowledging how the two secondary themes feed into these. Each theme will be examined in turn. The meaning will be interpreted with reference to the relevant literature, and it will be related back to the research question about how CB is constructed.
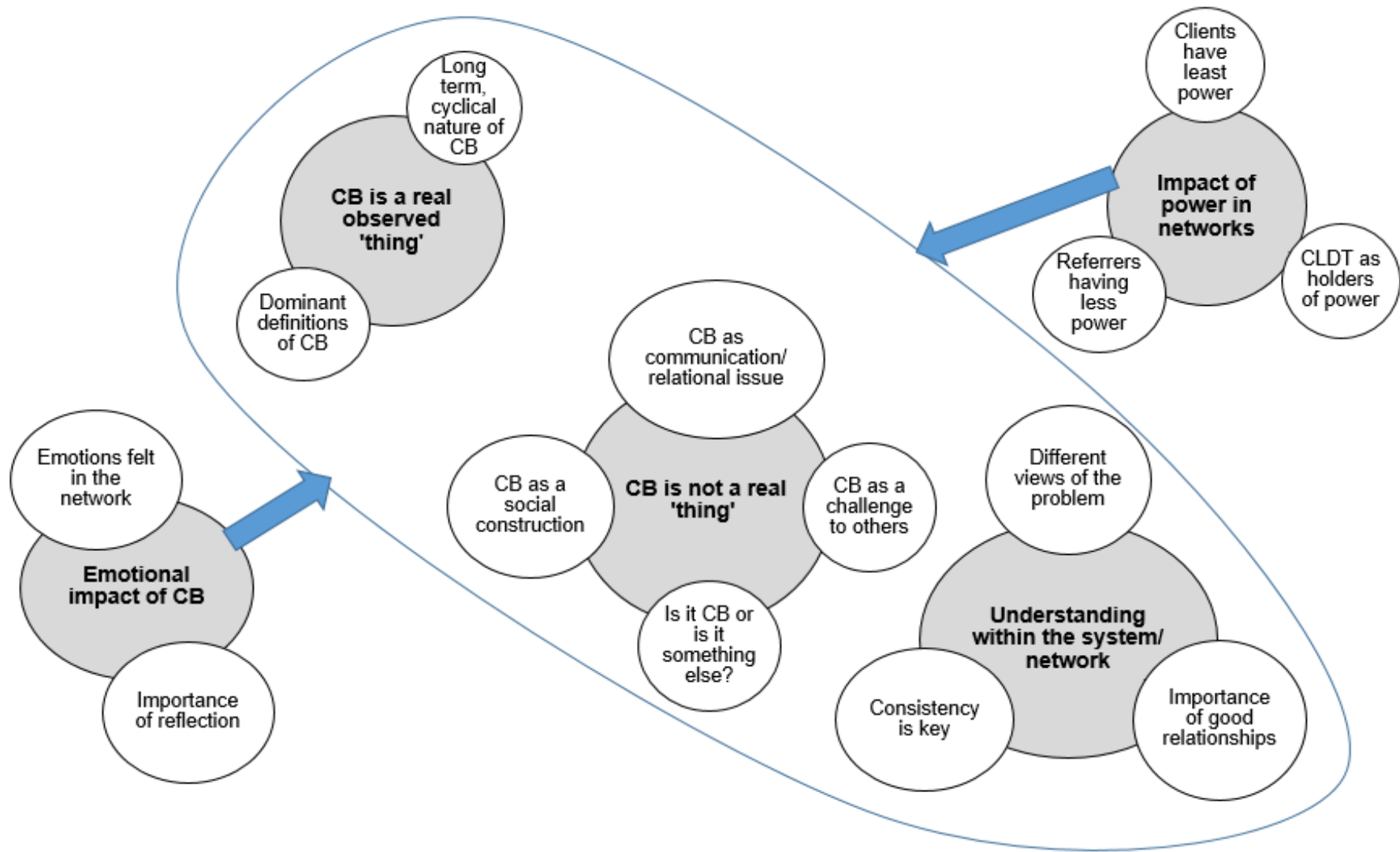
Figure 1: Thematic map of overarching and sub themes

3.2. Theme One: Challenging Behaviour is a Real Observed 'Thing'

3.2.1. Dominant Definitions of Challenging Behaviour

CB was talked about and understood in numerous ways by the referrers and CPs, but there were many commonalities. There was a sense by most that CB was a 'thing' that could be identified, observed and talked about. There were certainly some dominant constructions of CB that came out throughout the interviews. Some of these seemed to link to Emerson's (1995) definition, and nearly all of the CPs made direct reference to this when asked about their own personal definitions of CB, which suggests it continues to provide a model of understanding for professionals. Emerson's definition was spoken about as being a "formal" way of understanding (Annabel/28, CP), and it was acknowledged that it was something "people often use" (Rachel/34, CP) and "so trotted out" (Sandra/34, CP). This suggests some reluctance to fully accept this definition, perhaps it is an easily recalled way of understanding but less helpful in practice. Similar caution was raised by some referrers about using such definitions. Sam actively chose to reject recalling a formal definition and acknowledged the risks of using generic terms:

> I wanna use the right words here, I don't want to go over the top because that's another issues with challenging behaviour is the stigma (Sam/35, SW)

Despite these considerations, both the referrers and CPs found themselves talking about constructs that would fit in within Emerson's (1995) definition, some examples of which are described.

3.2.1.1. Severity: Emerson describes behaviour as being 'of such intensity', and all of the referrers and CPs gave examples of more 'severe' types of behaviours when describing what experiences would come under CB, as Hastings (1995) also found. These included verbal and physical aggression, self-injurious behaviour and sexualised behaviour, more typically 'outer-directed' behaviours (Lowe et al, 1995). They were discussed as being "the most obvious ones" (Sandra/59, CP). There may be ideas around referral thresholds and beliefs

within support teams, with behaviour needing to be of high severity in order to be taken seriously by the CLDT. Sam was mindful how common this is for people to automatically discuss more severe or physical behaviours first:

> what I didn't want the first thing that I mentioned would be about physical behaviours so people actually being physically violent, so that is when people mention challenging that's the first thing they hear (Sam/86, SW)

Severity can be perceived to be over-emphasised, and Annabel talked of the importance of looking beyond the 'severity' that is sometimes presented in referral forms:

> reading the horrific sounding referrals but then I guess once I got into it and I realised the people I was meeting actually, most of the time they're not behaving in ways that are written down on the piece of paper (Annabel/730, CP)

This suggests there is a dynamic between the referrers and CLDT, where behaviours perhaps end up being constructed as more severe, in order to receive support.

3.2.1.2. Community Access: Another common way of thinking about CB, in line with Emerson's definition, was in terms of being 'denied access to, ordinary community facilities'. Tony spoke about other community services rejecting a client, "because they couldn't cope with him" (Tony/41, SW). Kim spoke about behaviour directly impacting on community life, "staff are wary about taking people out, so it really restricts their community access" (Kim/98, CP) and ability to access the usual places that others are able to, "it's about people's capacity to access kind of the traditional, community services" (Rachel/77, CP). The restricted access participants spoke of seemed to relate to fear around supporting the person. The consequent impact on quality of life was discussed.

3.2.1.3. Risk: Emerson also suggested that the 'physical safety of the person or others is likely to be placed in serious jeopardy' when CB is considered. Nearly

all of the participants spoke about risk, in terms of how they came to understand a behaviour as being challenging. Safety seemed to be an important factor in constructing CB, "I think the support is for her own safety" (Alex/274, SW) to keep the person and others safe, "firstly for the safety of others we need to write a new programme for him" (Tony/161, SW). Ash spoke about safety being jeopardised as being the threshold to making a referral, "for his safety and everybody else's safety, so I immediately made that referral" (Ash/141, SW) as did Sam, "it came to a point where it was too dangerous for her, too dangerous for the support" (Sam/190, SW). Risk management was spoken about as being a clear reason why additional support would be needed. The CPs spoke about primary questions about risk that always arise, "is there any immediate risk?" (Sandra/75, CP) "what's the risk to themselves, other people or property?" (Annabel/58, CP). Risk was the main priority above all else:

> we think about risk ultimately, if the behaviour is significant and the client's getting hurt or someone else is getting hurt, that's really ultimately what we think about and the rest is secondary (Kim/133, CP)

There was consensus in both groups that risk is an important thing to think about when trying to make sense of CB. Perhaps this is due to the high emotions that can surround risky situations, "a lot of high arousal about the level of risk, associated with him" (Rachel/240, CP).

3.2.1.4. Complexity: Another commonly shared view was that in order to be understood as CB, it would usually be described as complex. The CPs spoke about multiple interventions occurring alongside each other, for example, capacity assessments or safeguarding procedures. Interventions involve understanding patterns and peeling back layers, "they're often even more layered than you might anticipate" (Rachel/356, CP). There was a sense that this is to be expected in CB work:

> I have this naïve aspiration that there are these straight forward challenging behaviour referrals [laughter] that come through where you assess, you intervene and then you close, I don't ever seem to have that…

the intervention always tend to be very multi-factorial and that's what the recommendations are (Rachel/350, CP)

Although Rachel spoke in a light hearted way about desiring a straight forward case, this multi-factorial way of working was something all of the CPs spoke about as being their standard way of working. PBS is a recommended intervention for CB, but it isn't necessarily suitable for all. Kim raised how the majority of the referrals they had received were far more complex than this:

30-35 referrals for challenging behaviour in the last year, only three of them had 'straight forward' if you can ever call PBS straightforward, but more traditional PBS (Kim/231, CP)

The referrers also spoke about complexity. Jamie had an understanding of always looking beyond the behaviour, "it can be raising a red flag…but it's so much more complex than that" (Jamie/515, SW). It seems that complexity is intrinsic to how CB is understood. Without the complexity, perhaps it would be named or constructed as something else.

3.3.1.5. Stigma: A result of numerous discourses and ideas around CB is stigma. The CPs spoke about "weariness" (Sandra/213, CP) of getting involved with clients with long histories of CB and clients being described as "notorious" (Annabel/231, CP) or causing a "heart sink" (Sandra/220, CP) feeling. There were discussions about how, when a label for CB is placed, it "overwhelms all other thinking" (Jay/237, CP). Similarly, the referrers spoke about stigma attached to the label:

people just take a step back and think oh what is this challenging behaviour, and it's like well so and so once hit a support worker…and you're like, do I want to work with this person? (Sam/92, CP)

3.2.2. Long-term Cyclical Nature of Challenging Behaviour

In order for behaviour to be understood as challenging, there seemed to be an understanding in most of the participants that it had to have some permanency across a person's life (Totsika, et al, 2008). Behaviour that reoccurs, possibly causes more frustrations or helplessness in networks, and so is more likely to receive the label of challenging. Referrers spoke about people having, "always been quite challenging" (Sam/183, SW) and issues being "bounced back and forwards endless times" (Charlie/333, SW). They also noticed patterns, "It had been going on sporadically, you know it would be once a year, maybe twice a year, there was a pattern there and a history" (Jamie/154, SW). This kind of thinking perhaps leads to referrers having an expectation that CB will always be a part of a person's identity, "that's the way he has been, they have been all their life" (Tony/550, SW). This understanding would inevitably impact on how they interact with the people they support and the kind of hope that exists for interventions. Charlie spoke of the frustrations of discussing the same issue:

> you will deal with again exactly the same problem and you will go through the same process of having the same conversations (Charlie/122, SW)

The CPs similarly spoke of a sense that some people will be indefinitely challenging, "she's still challenging, she's going to be forever really" (Kim/525, CP). Whilst with the referrers, there was a sense of frustration with the same issues arising, the CPs spoke about how it is to be expected that some people would require ongoing support, "I don't tend to do short term work" (Rachel/425, CP) and might never be discharged:

> those people who are, I want to say 'properly challenging', the people who really have the greatest need, I don't think we should be discharging them (Kim/178, CP)

The CPs' views were not dissimilar from one another, perhaps due to their training and having more overt influence from policy and guidance. Some spoke about guidance directly, "I've been very influenced by guidance from Jim Mansell,

thinking about how challenging behaviour, is understood and constructed" (Rachel/48, CP). Kim highlighted that sometimes guidance doesn't pay attention to how support teams and CLDTs are supposed to work together:

> there is no mention of that interface really because I think sometimes it says 'more people should have this or they should have that' and it's like yea but who's responsible for that? (Kim/838, CP)

There was slightly more diversity in the referrers views, perhaps due to being more influenced by wider discourses in society about behaviour. It was noticeable that some of Tony's views differed significantly, for example, about the use of restraint and choice of language, such as describing other people as 'victims' of the client. Tony described not having any training on CB in more than 15 years. This is reflected in the discourses he was drawing on that were perhaps more commonly accepted in previous decades.

3.3. Theme Two: Challenging Behaviour is Not a Real 'Thing'

3.3.1. Challenging Behaviour as a Social Construction

In order for a behaviour to be viewed as challenging, it depends on different assumptions and expectations the observing person has as a social being. Despite using many common discourses to talk about CB, the majority of participants talked about CB as being not something a person 'is' or 'has'. It arises in particular contexts and is defined and responded to by others within those contexts. This felt like an important point that many wanted to highlight, "there's not like there's a generalised expression of it…it can be very individual" (Charlie/45, SW); "it's individual to each client and it's very complex" (Jamie/38, SW). It was viewed by Rachel as being "a catch all term that relates to some sort of problematic behaviour" (Rachel/33, CP). Jay described how easy it is for people to accept labels:

> I used to take it for granted that there was a thing called challenging behaviour and that people did this thing and that they were this thing and they presented with this thing (Jay/678, CP)

He also had ideas about how using a label such as CB marginalises people, and people can become "a repertoire of behaviours" (Jay/19, CP); behaviours become the main focus over any other part of a person:

> it marginalises people with learning disabilities and sort of devalues their emotional worlds, because we think when we label things like people's behaviour that becomes kind of a common, quite a problem saturated narrative (Jay/13, CP)

This fits with Antonsson et al's (2008) ideas around an 'I-it' relationship, where staff and clients see each other as isolated qualities, with distance and detachment.

Behaviour can cause networks to struggle, look for short cuts, look for quick answers or try to reduce the behaviour without understanding it. It was noticed that as soon as a generic label, such as CB, is attached to a person, it becomes easy for teams to think there is a generic response that can be rolled out in a similar way. A PBS response may be appropriate for some individuals, but it isn't as simple as applying it to all:

> my worry is that a bit like with CBT what's going to happen is people like the Government, certain providers or whatever will go 'PBS is great let's do it with everyone' and actually I don't think that's helpful (Kim/759, CP)

> the right level of intervention so that it's you know not a full major functional analysis for every single occurrence of challenging behaviour (Sandra/89, CP)

This sheds different light on Allen et al's (2005) review that suggested that despite PBS having the best evidence base, it is used infrequently. Perhaps staff

are using elements of a PBS approach, but they are needing to draw on much wider resources due to the complexities.

There was agreement from both referrers and CPs that some CB is just behaviour, as we all can be challenging at times, and networks should be mindful of this:

> there'll be some time when someone does something just because people do stupid things don't they, just because you're disabled doesn't mean you can't be stupid (Sam/711, SW)

> first we wanted to also, make it clear to the service user that this behaviour was not abnormal, this is entirely normal behaviour (Charlie/414, SW)

> a certain amount of challenge will be there and kind of acceptance that actually we need to work with that (Sandra/130, CP)

3.3.2. <u>Challenging Behaviour as a Challenge to Others</u>

The majority of people interviewed had a shared understanding that CB is not something that is internal to the individual; it is socially constructed and perceived through the eyes of others. CB comes to be talked about because it presents a challenge to the people around the person, not usually because the person themselves is highlighting it as a problem:

> it's often not the person whose name you see on a form who has a problem, it's usually people around them (Annabel/23, CP)

> we tend to see less people who identify it as a problem for themselves, it would probably get called something a bit different, it's usually when it's someone else defining it as an issue (Rachel/42, CP)

There were commonly used ways of speaking about behaviour being a challenge to others that show perhaps dominant discourses have moved away from the

behaviour being seen as internal. Both the referrers and CPs used similar ways to talk about CB being a challenge to themselves and services:

> the behaviour comes from the client but it's challenging in that we don't understand it, or that we find it difficult to work with that (Jamie/22, SW)

> challenges people around the particular person with a behaviour or services around, so something that other people find disturbing, difficult and find hard to manage (Sandra/36, CP)

3.3.3. Is it Challenging Behaviour or is it Something Else?

Behaviours might be expressed for a multitude of reasons, yet often gets labelled with the overarching term of CB. The concept of diagnostic overshadowing, when behaviour relating to pain or physical health problems is attributed to the persons disability (Robertson, Roberts & Emerson, 2010), was discussed. All of the participants discussed the importance of investigating any underlying physical concerns:

> I normally find that a lot of the time when someone's challenging it may be because they're not feeling well and as they're not able to say, I've got a headache (Sam/204, SW)

> we found that the reason she was behaving that way was because she wasn't really well at that time and she had a chest infection (Alex/205, SW)

> he's really prone to ear infections and so the increase in head butting was possible also linked to an undiagnosed ear infection (Rachel/223, CP)

Another example of behaviour that frequently gets constructed as challenging, is expressing dislike or an opinion through their behaviour (Distasio, 1994). This would make sense in the context of busy support environments, where someone acting against the norm can be disruptive to routine (Drinkwater, 2005), for example, "he has a challenging behaviour because he was not ready to respond to what other people want him to do" (Tony/107, SW). This fits with Hayden and

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Stevens (2004) ideas around 'non-compliance' being most the commonly reported CB.

3.3.4. Challenging Behaviour as a Communication/Relational Issue

Viewing CB as communication, rather than just a set of behaviours, was considered by most of the participants, and appears to be a commonly held discourse (Hastings, 1995):

> it's always been instilled in me quite early on that challenging behaviour is mostly about communication and you know I've seen nothing to dissuade me from that (Sam/706, SW)

> they can't communicate verbally so they try to communicate with you in a physical way (Alex/36, SW)

> the first question that I ask myself is what are they trying to communicate (Sandy/744, CP)

CB was commonly described as something that happens between people. It is a communication issue, not just on the part of the individual who is trying to communicate, but also in the person who is struggling to understand:

> this person's trying to communicate something to you, you're not understanding what they're saying, so they're trying to tell you in a different way (Ash/27, SW)

> if they feel like they're not being understood, it can be quite frustrating for them, so we need to find out, put things in place to make life easier for them (Alex/163, SW)

This fits with Antonsson et al's (2008) ideas around staff having to guess and mentalise what clients are communicating, which may be very different to how they think, and can lead to feelings of inadequacy and lack of self-efficacy. It also highlights Davenhill's (1998) ideas that if clients do not feel their feelings are

understood, they may respond in aggressive ways because their feelings may be too difficult to tolerate. This takes a psychodynamic perspective and adds further understanding as to why staff might feel inadequate, if the individual splits their intolerable feelings from themselves to the staff member. Support staff need support to process this complicated communication.

Behaviour being an indicator of someone's emotional or internal states, was also spoken about by both referrers and CPs. The individual may use what skills or resources they have to communicate a message about how they are feeling:

> when he was very anxious or possibly even in pain and it could be a kind of a communication also at times for him to actually show us that he's very anxious (Charlie/291, SW)

> all challenging behaviour is communication but it's just communication of emotional states or kind of specific needs (Jay/37, CP)

It was highlighted that it is often easier for people to look at what is presenting, rather than why it might be presenting:

> people adhere less to what might be occurring in the emotional world of people or the internal world of people (Jay/17, CP)

3.4.   Theme Three: Understanding Within the System/Network

This theme highlighted how understandings of CB in PWLD can only occur within the systems and networks, where the person labelled with CB is supported. There are inevitable differences between services, the training staff receive and individual differences that all contribute to how CB might be understood in different ways. Paying attention to these differences and focusing on relationships within the network, was spoken about by all participants.

<u>3.4.1. Different Views of the Problem</u>

The majority of referrers and CPs spoke about the differences in understanding CB that occurs in networks, within teams and between teams. These differences were highlighted by referrers as being a challenge. Tony spoke about 'within team differences', where some staff might observe behaviour as challenging and others may not; "such a thing doesn't happen with me but with others" (Tony/172, SW). Jamie discussed 'between team differences', with an example of the psychologist giving a view point at odds with the supporting team:

> I didn't actually find that the psychologist was particularly insightful in that, perhaps because it may be that they were newly qualified (Jamie/379, SW)

Jamie looked for reasons why there might be differences in this relationship, which suggests there is usually a goal of reaching a consensus between teams. Even if the referrers judge their way of thinking to be more correct due to their experience with the person, there may be things that stop them raising or discussing the differences. Perhaps this is due to power imbalances across the network. Ash spoke about dilemmas of raising difference in network meetings, so as to not upset anyone or damage relations in the network:

> you've got lots of different people and sometimes it's difficult to say, I find this really frustrating, because you can only say that by upsetting one of them, and you don't wanna upset anybody so sometimes you're kind of forced to kind of, not say anything and just keep a little bit quiet and try and try and word it another way (Ash/508, CP)

Again there seemed to be power dynamics at play here, where there is a perceived pressure for the support worker to do what is expected. Ash described his view of what psychology want, "they want to hear everything's going and everything's working" (Ash/535, SW). Many of the referrers spoke about how difficult it can be when it feels like psychology do not get a real sense of what is happening for the individual and the team. This is often due to the lack of perceived time spent really seeing or hearing what the situation is. A CP was

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described by Tony as, "coming for the first time and seeing somebody and just making judgement, that OK it's fine, let's just do this, do that" (Tony/205, SW) and by Jamie, "that psychologist that I was dealing with only saw it from one angle and didn't see the whole picture and quite dismissive really" (Jamie/390, SW). Ash further highlighted frustrations in relation to psychologists giving advice from a distance:

> it's OK for you to say this, you're doing it by the book, you're not doing it practically you're not actually there, you're not actually working with this person (Ash/425, SW)

There were some ideas of psychology being in a position of power to tell the support teams how to respond and act, "they're psychologists and that's their job, you know they tell you, do this, this and this, so do it" (Ash/548, SW). This fitted with Hare et al's (2012) ideas around the CLDT being in the position of power to 'empower' others. Tony also highlighted how it can feel as though psychology can simplify the complexities of what it is like supporting a person:

> they just write a report that OK we have seen Peter, we have done a bit of an assessment and we have realised that if the staff follow the guidelines everything is fine (Tony/647, SW)

There was also discussion about the frustrations and disappointments with the input received from psychology, by some of the referrers. There was perhaps an expectation that psychology should be offering something new, unique and useful to the team, and sometimes it feels that this is not the case. Ash described this frustration:

> you were just rebounding that idea back off me…I'm giving you an idea, now as psychologists give me, critique it back, tell me where it's going to go wrong, tell me which bits should I be looking out for, tell me you know how I can adjust it (Ash/374, SW)

He also described how intervention can feel repetitive and unhelpful at times, "sometimes I get a little bit frustrated with that, because I'm thinking, why are we going through the same thing, again" (Ash/418, SW). Tony described disappointments with guidelines that can feel imposed, "what she wrote, staff were not quite pleased so we have to make additional referral" (Tony/204, SW). The barriers to implementing guidelines fitted with McKenzie et al's (2005) findings, for example seeing them as not fitting the problem. Jamie spoke about feeling left by the psychologist to complete the work with little support:

> this is the amount of time I can spend, and sometimes you can feel well you're the one going, you're here and you're visiting, OK great but when you're walking out the door, I'm still here and so is the client, so yea I would I think more intervention and a longer length of time (Jamie/573, SW)

These ideas suggest perhaps there is something communicative occurring. Either the psychology team are not communicating effectively why they are working in the way they do, or the support workers are not understanding or agreeing with their decisions, but feel unable to say so. Shein's (1996) ideas about the 'engineers' and 'operators' resonated here, where the 'operators' feel distrustful of the 'engineers' involvement.

A common belief that the CPs believed the referrers have, is to remove the behaviour, "people just want that magic wand we don't actually get given ever" (Annabel/201, CP). Jay also shared this view "they just wanted for us to come and partly just take it all away…get rid of it and stop the behaviour" (Jay/348, CP). In fact the referrers seemed to have similar ideas to the CPs, "I never believed that a magic wand would come out and things would automatically get better" (Sam/470, SW), "it's not a magic wand but they always you know are so helpful" (Jamie/411, SW). There are lots of beliefs and assumptions services make about each other, but often they are thinking in similar ways and perhaps are not aware of this.

3.4.2. <u>Consistency is Key</u>

The importance of consistent methods and responses to CB, was a commonly spoken about theme throughout the majority of the interviews. It appeared to be valued by both CPs and referrers. The referrers seemed to put that decision making capacity more with management or the CLDT. Sam spoke of wanting a manager to impose the consistent approach and say, "we're doing it this way, no arguments, this is how it needs to be done" (Sam/381, SW). Alex spoke about the importance of following guidelines "to the letter because if you don't and you miss a cue then there could be a problem" (Alex/421, SW). Sam spoke of the process of creating a consistent approach within a team as essential:

> you get some people who think, 'oh that's not the way we should be doing it', even if they're right, that's not the point you need to be consistent as a team, if it doesn't work then you change, then you be consistent in another way, you can't just have people going off doing their own thing, otherwise how can you be sure that we've done everything we can do, if we're not consistent as a team (Sam/405, SW)

Charlie agreed that there needs to be an agreed response throughout the team:

> what would be a good sort of response for, that we can all sort of agree on and the agreement that people kind of felt comfortable with (Charlie/407, SW)

The CPs also spoke about making an attempt to get consistency and "trying to get a sense of what the consistent ideas were and where the inconsistencies were" (Rachel/289, CP), for the benefit of the client, "making his world much more predictable and creating greater consistency" (Sandy/341, CP). Kim highlighted how this consistency needs to feel shared across the network:

> it feels like a much more team approach, in a wider sense so not just our team but we are a team with the provider and I think before it felt a little bit like 'them and us' and I think now there is a much more kind of that 'we are the team around her' including the family (Kim/526, CP)

These ideas resonated with Whitworth et al's (1999) ideas around the 'them and us' culture, between CLDT and support providers, and the importance of working on this. Being a cohesive team feels instinctively helpful, as if the network is spending more time resolving their own differences, it takes away focus from the intervention. Although becoming a cohesive, consistent team is often a helpful intervention in itself.

The consequences of staff teams not having a shared way of working were discussed. Ash talked of the heavy reliance on every person in the network, "it just takes that one person to not do their bit and then the whole lot collapses" (Ash/440, SW). The idea was raised that usually problems occur due to a lack of consistency, "where things go wrong there's often big inconsistencies in people's lives" (Rachel/314, CP).

The CPs spoke about inconsistencies often occurring where the system is struggling, and Rachel described it as a "knee jerk" (Rachel/126, CP) reaction to assume that staff are not following guidelines. This can also lead to a reluctance to continue involvement when teams do not implement the guidance that is recommended, "come on that's a basic, we're not going to get involved again" (Annabel/199, CP).

This links back to the previous discussions about the referrers not agreeing with how psychology intervenes. Both groups expressed frustration with the 'other', whether it be for not implementing guidelines or not spending enough time. This is further indication that there might be communication challenges or something else, such as power imbalances, which influence how CB is being constructed.

Inconsistencies in the form of frequently changing staff teams were raised, where "all of that experience gets lost every time" (Charlie/507, SW). Also, a lack of effective recording of clients' histories was raised as a concern for consistency. In general, having a single recorded history was seen as valuable. This is in line with Hare et al's (2012) study where they found that although staff teams might not have one voice, seeing the person in their historical context was most

relevant. A lot of time might be spent trying to pull together different strands of a person's life, due to inconsistent recording methods between services:

> nobody was really clear where did it go, there was no, it was very muddled, you couldn't make sense of what was actually decided (Charlie/218, SW)

Also, assumptions or labels might become attached to a person, due to only part of a context being recorded. Sam spoke about a person hitting a support worker and the label of CB becoming attached to him, but a good history can tell a different story, "OK this person did punch a support worker, but it's because they had tooth ache" (Sam/107, SW).

The CPs noticed similar problems with a lack of history taking:

> no one had a good developmental history, no one had a really good formulation around what was happening with this person (Sandra/189, CP)

> everyone had forgotten all of these things from the past, so we tried to reconnect him with some of his past (Jay/536, CP)

Even when a history is in place, it can tell a somewhat thin story about an individual, commenting on behaviours, with little acknowledgement of other things in the person's world. Jay described one historical record of a client he supported:

> 'had an OK day, bit one staff, had a warm drink before bed time' and it's just nothing, there's decades and decades of these notes, which just said nothing about him (Jay/533, CP)

It was discussed how easy it can be to fall into the dominant models of observing and assessing presenting behaviour:

we attend far too much to that empirical kind of paradigm of behaviour rather than what's happened in this person's life that they might be doing this particular thing, because nobody really thinks like that about people with learning disabilities. If I was doing that people would be like, god what happened in your childhood (Jay/229, CP)

Inconsistent environments were also reported as having a negative impact on CB, with environment being core to how CB is understood:

challenging behaviour as being a lack of fit with the environment and so the focus being on adapting the environment as much as possible to support people (Rachel/70, CP)

Clients often sit within many different environments, such as home, day services and respite. Charlie mentioned the importance of finding "approaches or strategies that can acknowledge all these different environments and hopefully that can be implemented in all these environments" (Charlie/461, SW). Jay spoke of creating "capable environments" (Jay/145, CP) in line with guidance (RCP, et al, 2007). Ash spoke about the responsibility being with staff, "how can we change ourselves or our service to help that person" (Ash/54, SW).

3.4.3. Importance of Good Relationships

Both the referrers and CPs spoke about the value in developing good working relationships across the whole network, which connects with the previous subtheme of consistency. Charlie spoke of "the benefit of collaboration, the sharing, pooling of information and experiences" (Charlie/455, SW), as did Alex:

everybody was involved in how to support that and it's really really good that she kind of actually developed and grew as a person…I think it helped with everybody working together for that one individual (Alex/453, SW)

Jamie spoke about techniques he has developed, to ensure close working relationships with networks "I've always had a very close working relationship

with the psychologist or psychiatrists" (Jamie/169, SW). His view was that by doing this, he gets a "much better service" (Jamie/477, SW).

The CPs too spoke about the priorities being to "make friends with those people and we have a mature grown up discussion about who's going to do what" (Kim/850, CP), "generally we know everybody, because we make a point of getting out there" (Jay/607, CP). Rachel described how their model of working is all about collaborative working:

> clinicians like psychologists and nurses will work alongside very experienced staff members to support people in the community…it aims to be a very non-pathologising way of working and really thinking about where people are at (Rachel/306, CP)

There was a desire from referrers for even more collaborative working, beyond the usual dynamic of making a referral and getting a response. Perhaps with more integrated relationships between referrers and the CLDTs:

> I would like to see it more a case of working in partnership together and you know not always just having contact with psychology when it's a referral or when you need help (Jamie/562, SW)

These ideas reminded me of Carnaby, et al's (2011) 'flexible response service', with clinicians and support staff working physically alongside each other, and Whitworth et al's (1999) idea of external professionals having more input to the day to day operations in support services.

3.5. Theme Four: Emotional Impact of Challenging Behaviour

Noticing and coping with difficult emotions was a theme that seemed to run through all of the interviews. Mostly, this was talked about in relation to referrers, but there was some acknowledgment of emotions felt within the CLDT. A subtheme also arose around the value in reflection.

3.5.1. <u>Emotions Felt in the Network</u>

A common emotion noticed in referrers by the CPs, was fear (Bromley & Emerson, 1995). Support staff were seen as "wary about taking people out" (Kim/98, CP) and "nervous going out" (Annabel/377, CP). There was also talk of referrers feeling "very cautious, very worried that they were not going to cope" (Sandy/247, CP) and "panicked" (Rachel/237, CP), to the extent of perhaps being severely affected "they are traumatised by a lot of these sort of experiences" (Jay/360, CP). Although this fear seemed to be spoken about in relation to the direct work with clients, it was acknowledged that it can be fear of blame as well, for causing or reinforcing behaviour , "they worried that they were going to get blamed" (Jay/340, CP). This fits with Haydon-Laurelut, et al's (2014) ideas of support teams feeling 'under surveillance' from the scrutiny of CLDTs.

The referrers themselves also spoke about fear being a common emotion, "I can tell you how I felt, terrified" (Ash/653, SW). Tony described other staff being unable to go out due to fear, "they be afraid that he might lash out to them or the public" (Tony/59, SW). It was also highlighted how feeling this level of fear can impact on the relationship with the individual labelled with CB, "if someone's constantly nervous around you, that's going to make you nervous" (Sam/101, SW). This view was shared by Jay, in terms of the transference and countertransference that can occur within the working relationship:

> their emotions really really projects into you exactly how that person is feeling so they're feeling frustrated that you find yourself feeling frustrated or if they're feeling scared, you're going to find yourself feeling scared as well (Jay/131, CP)

The referrers also discussed feeling "stressed, unhappy, demoralised" (Sam/374, SW). The normality of these emotions, and the importance of acknowledging them in the context of the challenging work, was also discussed with reference to the psychodynamic concept of repression:

it's OK to be frustrated, it's OK to feel helpless, it's OK to feel annoyed, because they're human emotions and if you don't acknowledge them then you're repressing them and that isn't healthy (Jamie/505, SW)

Only one CP directly acknowledged feeling anxious in relation to work with CB, "I remember feeling quite nervous before starting on this piece of work" (Annabel/294, CP). Others did, however, discuss feelings of being overworked and overwhelmed as a consequence of the complex work:

there is a huge toll from this kind of work and often there isn't enough, you sort of see people getting burnt out by it, because of the frustrations, not with individuals but with problems with systems (Rachel/657, CP)

the team's only human and feels very stretched and people generally feel over worked (Sandra/139, CP)

The consequences of this toll could perhaps be compassion fatigue, "you just don't try and do it anymore" (Rachel/668, CP). This is line with Maslach et al's (2001) description of burnout, as emotional exhaustion and diminished feelings of personal accomplishment.

3.5.2. Importance of Reflection

Both the CPs and referrers spoke of the importance of reflective space and of the challenges of finding this within the often over stretched context:

they're completely burnt out and having the space to think about their needs and what's going on is a luxury (Rachel/574, CP)

I think you can exhaust yourself where you just kind of think, my brain has gone dead, and in this case I don't know what to do (Ash/487, SW)

Some of the CPs spoke of prioritising offering reflective space and "making yourself available" (Jay/363, CP) to support teams. There was an idea around reflective space coming after an incident or a difficulty, "you really do need to go

in and just sort of debrief emotionally" (Jay/361, CP). Ideas around creating "safeness" (Sandy/442, CP) and "containment…listening to staff" (Jay/358, CP), were also discussed. Offering reflection was also seen as a way of enabling support workers to manage the challenges of their positions, "I think a role for us is I think supporting people to do the job" (Rachel/455, CP). Reflective space was not only valued in terms of reactive emotional support, but also to share ideas and experiences:

> that's why I think the staff work is really important, the reflective practice…because you can tease some of that out…I mean if one person's saying 'it's fine' it's like 'ok well what can we learn from your experience that we can share with the rest of the team' (Kim/380, CP)

It was, however, acknowledged that the CPs themselves may not have their own space to reflect, "there isn't always time for long reflective discussions" (Annabel/142, CP).

Most of the referrers spoke about the importance of finding reflective space in order to enhance understanding of CB but also for personal development, "we have to find some way to create reflective space within this environment" (Charlie/587, SW). In order for it to be beneficial, it was also highlighted that having space for reflection is something that needs to be a valued at a service level:

> it takes a kind of service ethos as well, and it will come down to individuals again, the particular manager or you know staff if people have the motivation or interest to go a little bit further (Charlie/605, SW).

Ash spoke about the use of a proactive 'reflecting team' approach that was found to be very useful, "helping me to reflect on my practice, you know and to kind of take, look at things with fresh eyes" (Ash/307, SW).

Jamie raised the point that whilst of course the client is priority, there are risks of not enabling space for those directly supporting the client to reflect, in terms of compassion fatigue or potential burnout:

> it was all about the client, the client, the client, and if you don't support the people who are supporting the client, you're on a slippery slope, because if they don't feel valued, if they don't feel listened to and supported, there will come a time when they'll just not want to give that level of care (Jamie/393, SW).

3.6.   Theme Five: Impact of Power in Networks

Power was talked about explicitly throughout most of the interviews; considerations about who is the holder of power, and the impact of a perceived lack of power on a system. At an implicit level, power was also a thread running through much of the discussions. Supporting a person with CB can easily become a power struggle, between client and staff, between support teams and CLDTs, and also between CLDTs and commissioners. This links in with some of the systemic challenges highlighted in Theme Three (understandings within the system or network).

3.6.1. Referrers Having Less Power
Many of the referrers spoke about how little power they have in sharing their own ideas and how referrals often have to go via management:

> it's a bit hard for me as a support worker to go to the head of psychology or the head of whoever and go 'I want this done' (Sam/670, SW).

There was, however, an acceptance of this hierarchy by the same person, along with the idea that support workers shouldn't be making those decisions:

> I don't think it would be a good situation if you get X amount of support workers making referrals that shouldn't be made, you know, I do believe

there should be that hierarchy in a sense, just to eliminate erroneous referrals (Sam/680, SW)

This fits with Nunkoosing and Haydon-Laurelut's (2011) findings that the managers sent the referrals and the voice of the support worker was absent. Ash highlighted that those doing the direct work often don't have power in making decisions about a person's support:

that's not me doing that, that's my manager doing it who obviously wants to take the glory for it, then he'll pass it over to me (Ash/541, SW)

It was also of note that Jamie took the interview as an opportunity to get his voice, and that of frontline workers, heard by wider professionals, "hopefully it will you know, get back to the people that you know are in psychology" (Jamie/589, SW). Feelings of powerlessness were also discussed in response to working with people labelled with CB, "I felt very disempowered as well because I couldn't really help my colleagues" (Jamie/359, SW).

The process of making a referral was discussed in relation to feeling at a loss for what to do and having no resources left, rather than a natural process between services:

it would be time to make a referral if it gets to the point where I'm finding it challenging myself, and I've lost all resources and you know I really don't know what to do next (Ash/68, SW)

Some referrers spoke about a negative meaning attached to support seeking or a feeling a failure if unable to resolve the challenge themselves:

it can come across slightly demoralising in a way because you've been working with a person, and yet you're still seeking professional help (Sam/252, SW)

> I mean ideally I would have liked to sort it out myself, my own self
> achievement (Ash/165, SW)

This is in line with Jenkins et al's (1997) findings that staff may feel a sense of failure, if unable to resolve a difficulty on their own. Jamie conversely spoke about an acceptance of being in a position of needing help from others:

> I need to make the referral in order to get help, perhaps that I can't give, or
> certain expertise or advice that I need (Jamie/76, SW)

Similarly Tony accepted that help is sometimes needed as a way of sharing the burden of responsibility with others:

> the professional advice rather than just using your own knowledge, I mean
> so that way we protect both parties (Tony/371, SW)

The CPs had insights into how disempowering it can feel as frontline staff, some from their own experiences working as support workers. It was acknowledged how difficult working in the field of CB can be for those in positions of perceived less power. Perhaps due to fear, "thinking that they're being kind of scrutinised" (Jay/380, CP) or due to perceived lack of skills:

> they did not have enough skills or support to manage his presentation and
> that he was constantly presenting with challenging, behaviour that
> challenged them (Sandy/295, CP)

It was also highlighted how understandable it is for support workers to have diverse understandings of CB, given the powerful discourses that can be at play, such as CB being severe, pervasive and complex. Jay spoke about how difficult it is for support workers to express different ideas or opinions, from his own experience as one:

I just sort of kind of assumed that was how things were and just took my lead from other people who were sort of much more senior…when you've got the possibility of being physically assaulted or hit or spat at or bitten…you do quite happily defer to another more senior or more kind in control type of figure...it's very easy to comply with these sorts of terms because if you go into it the kind of fear that you have going into a situation which is very unpredictable and dangerous…you're very open to other people telling what to do and telling you how to think (Jay/60, CP)

3.6.2. <u>CLDTs as Holders of Power</u>

In terms of where the power was perceived to lie in the system, the CLDT, in particular psychology, were viewed by some as being "at the top of the pyramid" (Jamie/229, SW). Many of the referrers spoke about how despite the CLDT or psychology having the most power in the system, often their role is to just confirm what the support teams are already doing, as Jamie described "I spoke to Doctor X and she said yea I think you're probably right" (Jamie/258, SW) and Tony "she just said you go ahead with what you're doing with her" (Tony/410, SW).

This was in line with Nunkoosing and Haydon-Laurelut's (2011) finding that referrals were made to confirm decisions that had already been made. For these participants it wasn't clear if it was empowering for referrers to have their ideas confirmed, or disempowering to be in a position where they need to have their ideas examined by an external team. For Ash it did seem to be a sought after response, "I just wanted psychology to basically say to me, yea you're correct" (Ash/200, SW).

There was some acknowledgement by the CPs of the power that psychology services can have in the network and the desire for this not to be the case, and not to be seen as "psychologists in the ivory tower" (Annabel/751, CP). Jay spoke about wanting to give away this perceived power:

ideally what you want is you want to phase out the need for any psychologists in the world, you know staff teams and families and people involved in people with learning disabilities to kind of have all of the

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awareness themselves to think things and solve their own problems
(Jay/699, CP)

Power is something that can infiltrate the system at all levels, and whilst the CPs
could acknowledge the impact of powerlessness on the support workers, they too
spoke about the frustrations of not having the power to make changes in services
at a higher level:

> Jim Mansell talked about it in challenging behaviour guidance from 2001
> about an implementation gap and we're still there, it's very frustrating to
> watch it and there's been all this government guidance about developing
> local services and we're just not feeling any change in kind of what we can
> actually offer locally…we don't have the kind of, clout as front line
> services, to be able to influence things. We used to have really good direct
> relationships with commissioning and for us that relationship has become
> much more distant so not having the opportunity to shape things
> (Rachel/605, CP).

3.6.3. Clients Having Least Power

It could be seen that there are struggles for power at all levels of the system. The
client has very little power over the support they receive and the level of scrutiny
they are under, as described by Sam, "there's people around you, in your face,
trying to do things, and you don't have that full control of your environment"
(Sam/74, SW). Sandy spoke of the level of surveillance an individual had, "they
had to have two to one with him, constantly sat by him 24 hours" (Sandy/263,
CP) and noticed how that close monitoring can reinforce behaviour. Sandra
acknowledged often networks can be "over involved in someone's life"
(Sandra/491, CP). This also fits with Nunkoosing and Haydon-Laurelut's (2011)
ideas around the impact of surveillance.

3.7.   Summary

In answer to the research question, I have described the interplay between the
three core themes and illustrated how the two secondary themes relating to

emotion and power, have a crucial role how CB is constructed. This will be explored further within the discussion.

4. DISCUSSION

4.1. Overview and Research Aims

This thesis aimed to address the question

- How is CB constructed by referrers and clinical psychologists in people with LD?

This chapter will examine novel findings of the study, with reference to the research question and relevant literature, and make recommendations for future research. Methodological limitations will be considered, and the study will be evaluated against standards for good qualitative research. There will a professional and personal reflexive account of the research process and the implications of the findings will be discussed.

4.2. Discussion of Themes

4.2.1. Theme One: Challenging Behaviour is a Real Observed 'Thing'

Many LD services are set up with specialist CB pathways, and so it is understandable that both CPs and referrers both talk in ways that suggest CB is something that can be understood. This encourages a view of aberrant behaviour as being separate from other behaviour, which fits with Peter Kinderman's (2016) recent ideas about 'abnormal psychology' being unhelpful, as we all use the same basic processes to understand the world. Having services set up in this way could be seen to create cultures that tell of pathological services users, rather than stories of empowerment (Nunkoosing & Haydon-Laurelut, 2013).

Many of the participants spoke critically of using standard definitions and labels, due to fear of increasing stigma by using generic labels. This suggested a heightened awareness of the same concerns of Jim Mansell (DoH, 2007), that there has been an inappropriate drift towards the term CB becoming an individualising label. Given that many participants still referred to dominant

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definitions, despite concerns about usefulness, suggests that there may be a preferred future of not using labels to define something that has such diverse underpinnings, but the influence of such dominant discourses are hard to shift. This fitted with Hastings' (1995) findings that although many people describe CB as being a systemic problem, they still hold views that the behaviours are intentional or need to change, which is at odds with a non-individualising view. Staff might therefore have an uncomfortable 'cognitive dissonance' (Festinger, 1957) that might lead them to leaning toward the most dominant understanding, to reduce this feeling.

Many acknowledged that disability is a social issue, but by distress being responded to by 'experts in disability', it sends a conflicting message that it is internal and in some ways related to the disability (McIntosh, 2002). This relates to the 'double bind' of having the label of CB; it can provide access to support through the specialists, but also marginalises and separates the person from society (Ingram & Lovell, 2011).

4.2.2. Theme Two: Challenging Behaviour is Not a Real 'Thing'
Many participants were keen to present an alternative view to the dominant ideas around CB. The CPs were more overt in this, which was expected, due to knowledge of the damaging effects of labelling and marginalisation that is inherent in the CP training. This story was also very present in the referrer group, with descriptions of CB, as being the system's problem, which was less expected. All participants were eager to highlight the diversities and complexities of the challenges they face, and the idea that CB is not something that can be generalised or, in fact, understood. This suggests shifts in the field whereby understanding of the system is being challenged, and not the person, is a shared view in different settings.

With the numerous underlying causes or difficulties that can become labelled as CB, it left me wondering what actually is understood to be CB? Is it a description for something when there is no clear underlying cause? Is it when there is an underlying cause, but the network needs support in deciphering what it is? At a

broader level, is it anything that other people are struggling to cope with or need help with? Which begs the question, why are we still putting the label on the person, if it is not the individual's problem, or if it is understood to be a relational problem? It is comparable to labelling a person speaking a different language as challenging, which seems absurd, rather than considering it as a communication challenge between people. Yet it seems services can still be stuck in this dynamic.

The subtheme of CB being a communication, usually of some internal distressing state, was shared by many. It could be interpreted that support workers act as containers for the difficult emotions the client experiences. Staff have to work harder to understand the countertransference that the person has sent to the support worker to contain (Bion, 1959) often due to difficulties in verbal expression. If a staff member is unable to bear the communication, a more disabling process starts; defences might arise, the staff member may distance themselves, the individual's feelings might not be contained and they may feel more distressed.

In summarising this theme I was taken back to Bogdan and Taylor's (1994) view that we should abandon labels altogether, and to look instead to society and service systems for what is happening within them. What strikes me about this is that that idea is more than 20 years old, yet somehow we are still in a position where individuals are labelled and services are constructed around that individualising label, even though many people do not agree with it. Services continue to get stuck in these marginalising cycles. There remains the question as to why the support that is offered by CP's is still categorised as being part of what is often called a 'CB pathway', if it is acknowledged to be something between people and not a problem internal to the person. The relational and systemic aspects of the work has been highlighted through the presenting themes, more so than any internal discourses, so why would an individualising label continue to be used? Perhaps psychology teams within CLDTs should be considering themselves as experts in relationships, rather than experts in disability or CB.

Given these ideas, it suggests that maybe understanding is not the obstacle to CLDTs and referrers successfully working together, which was a surprising finding.

4.2.3. Theme Three: Understanding Within the System/Network

Making sense of CB was unsurprisingly found to occur within the large and diverse networks people are within. CB could only be understood in the context of others. Participants spoke about the value of close, cohesive and consistent relationships, to enable the individual to be fully supported.

Differences and disappointments were expressed with how they viewed each other as services. The referrers were somewhat polarised in seeing psychology as either very helpful or inadequate in the support they offer. The CPs presented the common stereotype of support workers not following guidelines. This made me think of potential transference and countertransference within the system. For example, the referrers feeling frustrated about lack of support, the CPs feeling frustrated about the support not being taken up fully, which may offer a window into how the client, with the least amount of agency, is feeling. Although there was the shared acknowledgement that CB is complex, there was somewhat 'all or nothing' thinking about the dynamics between services, rather than seeing it too, as complex.

Whilst not advocating for paternalistic approaches to working with PWLD, a parenting perspective does offer some interesting ideas when thinking about the dynamics that exist between referrers and the CLDT. Maccoby and Martin (1983) describe styles of parenting based on the dimensions of demandingness (control, supervision) and responsiveness (warmth, involvement). From the perspective of some of the referrers, the CLDT may have been felt as absent and disinterested or 'permissive-neglecting'. Others had the sense that the CP role was to tell them what to do and described feeling unable to say when they disagree with those ideas. This fitted with an 'authoritarian' style, one of clear rules and structure. Whilst not suggesting a parenting model should be adopted in this context, it is interesting to note that according to Maccoby and Martin's (1983), it is warmth

that is missing from these styles. Perhaps a focus on relationships and increasing human connections in the system could be of use. This led me to think about working alliances within networks and whether there is enough tuning in with each other. Often a task is agreed, such as a behavioural plan and guidelines, but there are not always the resources to spend the time focusing on relationships and the emotional impact of those relationships.

4.2.4. Theme Four: Emotional Impact of Challenging Behaviour

The impact of strong emotions in a network was a theme shared by the majority of participants, particularly with reference to the referrers. There is perhaps an implicit expectation that due to the training and support structures (such as supervision) that CPs have, they should be able to contain and manage their emotions. The referrers on the whole were able to think about their own difficult emotions, but some seemed to struggle to mentalise what others in the external network might be feeling. This suggests a dynamic whereby the referrers feel strong emotions, and the CLDT's role is to be the holder of them.

Even if a person is unable to verbally communicate, there are often complex emotional structures intact, meaning a person with severe LD may feel emotions in the same way as anybody else (Stokes, 1987). In order to be in a position of true empathy to these emotions, staff must deal with their own difficult emotions. There was an understanding, in both the referrers and CPs, of the role of transference and countertransference in how closely linked personal emotions and that of the clients might be (Davenhill, 1998; Wagett, 2012).

Most participants spoke about the value of reflective space to think about their own feelings, and to think about the emotional world of the client. The goal of this space was identified by the CPs as being containing, offering a debrief post-incidents and creating a sense of safeness. There was a sense that whilst reflective space was valued, it is hard to find the time to do it within contexts that had competing priorities. It seemed it was seen as a luxury with other more 'urgent' issues taking priority. With services often stretched for resources, reflective space is often the first thing to go. This inevitably has an impact on how CB is constructed, if strong emotions are being felt and there is not the consistent

space to support their management. The CPs seemed to consider the emotional worlds of the client as priority, as would be expected. It seemed more challenging to find the resource to fully acknowledge the emotional world of the referrers.

Given the importance afforded to the system within this study, it might be useful to consider how systemic approaches might enable more reflection. This would allow staff the space to reflect on their emotions and relationships with clients (Rhodes et al, 2011; Allen, 1999). Systemic thinking in this way invites the referrers and referred to make more sense of their relationships (Haydon-Laurelut & Nunkoosing, 2010). Having supportive and positive relationships are essential components to a person's wellbeing (Nunkoosing & Haydon-Laurelut, 2013). PWLD do not have the same range of wellbeing experiences as the general population (McGillivray, Lau, Cummins & Davey, 2009). Thus the focus on genuine human relationships between staff and clients feels important to enable PWLD to experience heightened wellbeing. This could be through connecting people to networks of social relationships and enabling the person to find meaningful and fulfilling experiences that connect us as humans (Nunkoosing & Haydon-Laurelut, 2013).

4.2.5. Theme Five: Impact of Power in Networks

It was not surprising that a theme relating to power emerged from the data, given how power can impact on PWLD's lives at all levels. Foucault (1977) talks of power relations arising, whenever the actions of one person affects the field of possible actions of another. When a client tries to test the power of the routine, the resistance is often described as troublesome and labelled as CB (Nunkoosing & Haydon-Laurelut, 2012). Some of the practices employed by support staff, such as the surveillance and routinisation of client's lives, can function to defend against anxiety in the system (Menzies-Lyth, 1960), by enabling emotional distance. This may operate as a defence against loss and the painful reality of disability.

Ideas were raised about the CLDT being in a position of having most power in the network. CLDT's could be seen as having as a moral authority to define problems, and to propose solutions based on their observations. Making the

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referral acknowledges the authority and knowledge of the CLDT (Haydon-Laurelut et al, 2014). There were conflicting ideas from referrers about this. The idea that hierarchy is necessary as networks can become exhausted of ideas was present, but there was also frustration when it was perceived that no new opinions are offered, or not enough time is spent. Referral making can be invalidating to the knowledge of staff, due to the way the CLDT are viewed as coming in to 'approve' what the team are already doing (Haydon-Laurelut et al, 2014).

In historic institutions, power sat with a medical superior and filtered down through the staff, with the patient having the least. There continues to be a dominance of professionals, who have 'expertise' now; Hamlin and Oakes (2008) talk about the desire of professionals to hold onto this power because this 'expert' knowledge is valued in the system. Contrary to this, the findings show the CPs' uncomfortableness with power and desire to give it away or share it with the network. On a different note, the CPs spoke about the frustrations of lacking power with commissioners and not having the influence to make changes to services.

The clients, discussed within this study, were often placed in positions of having the minutiae of their lives being observed, judged, monitored, restricted and discussed in open forums (McIntosh, 2002). Clients are often those who are afforded the least amount of power and agency in the network.

There was a shared common powerlessness felt by all in this study. If every player in the system feels powerless, it is important to formulate what is occurring. There may be apathy and a sense of organisations reflecting the difficulties of each other. There is perhaps the shared view that the process of referral making is not helpful because it maintains power dynamics, and perhaps this should be replaced by something where the power is shared. This fits with the genuine collaboration that some of the participants spoke about, working alongside each other in partnership (Carnaby et al, 2011), and not having 'experts' in CB. Most importantly, is considering what it feels like to be the client with the least amount of power.

<u>4.2.6. Summary of Themes</u>

The motivation for completing this study concerned the idea that CLDTs and support services might have different understandings of CB, and this can create ruptures within systems. Given that systemic working is so intrinsic to this client group, and there being the mutual dependence between services, I felt this would be interesting to explore further. What the findings highlighted, was that despite the differences in training and experiences, both the referrers and CPs had very similar constructions of CB, which I did not expect. I expected the referrers would refer more to dominant discourses of CB, and the CPs to refer more to the idea of CB being a social construction, when in fact both groups spoke about CB in these ways. Both groups spoke of similar value in working within systems, and there was a shared agreement in the importance of collaboration and consistency.

Despite the similarity in perceived understanding of CB, both groups spoke of frustrations with the 'other'. This schism was interesting as understandings or constructions of CB did not seem to be at the root of it. It led me to reflect that something else was not being attended to, and whether it is the role of power and emotions within a network. Emotions were talked about as being important by nearly all participants, and there was shared value to having reflective space, but this seemed challenging to create. A model of understanding CB as emotional distress that highlights relationships, not diagnosis, continues to require attention (Lovett, 1996). Understanding may be shared, but if emotions are not attended to across the network, the ability to work well as a system is compromised. Equally the shared feeling of powerlessness in the systems was unsurprising, given that many of the same issues have been spoken about for many decades. Change seems to be very slow within services, let alone within wider society.

I would argue that the human aspect of the work that is carried out needs to be emphasised; mentalising what it is like to be the person labelled as having CB. The staff-person relationship should be the priority. It seems that many people see CB as a questionable and perhaps unhelpful construct, but the methods that are being used in services, are replicating old ways. Support staff are still making referrals, CLDTs are still utilising behavioural models, yet many acknowledge it is

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never as simple as that. Something needs to change for this schism not to exist, and it could be concluded that a focus on emotions, relationships and power could be the key.

4.3. What This Study Adds to the Diversity of the Literature

This study adds to the few studies that have looked to the views of support staff. Nunkoosing and Haydon-Laurelut (2011) have discussed the need for more research with the paid staff who make referrals to CLDTs, and to consider how this dynamic affects how CB is understood. This research has given voice to support workers who make referrals, as opposed to the views of managers only (Haydon-Laurelut, et al, 2014). This is important because, as this study has found, power has a significant impact on how CB is thought about. Support workers tend to have more 'hands on' roles than managers, so naturally they have different views due to the impact of the work. This study offers a different perspective, as it is looking at support workers at day services, whereas previous research has looked at the residential staff perspective (Haydon-Laurelut, et al, 2014). Individuals with LD might spend a significant proportion of their time at day services, so the views of staff here felt important. Another novel perspective in this study was the inclusion of CLDT members as 'responders' to referrals, specifically CPs. There has not been any research that looks at how CPs construct CB, and this gives an interesting comparative angle.

4.4. Recommendations for Future Research

Further research with a similar approach to the one taken in the presenting study could provide different insights, including staff from more diverse agencies and backgrounds, for example, respite services. It could also look to explore the views of different members of the CLDT, including speech and language therapists, occupational therapists and psychiatrists. Another important avenue for research is the meaningful engagement of families. It could be interesting to look to at how families construct CB, which was beyond the scope of this study.

Learning about their views of interventions and support they have received would be interesting.

Future research could also benefit from looking at what more relational and systemic type approaches for staff look like in practice and evaluating the success of these, together with considering the practical considerations of implementing these more consistently.

It would also be important to consider ways of including the voice of the person labelled with CB in research, perhaps findings novel ways to ask people about the relationships they have within their networks. This could be through the use of 'talking mats' to access ideas from individuals who do not use verbal communication. The idea of using life narrative research, is also interesting, by considering the person's unique identity and history, it enables them to be seen as a person not a set of behaviours (Nind, 2008).

4.5. Limitations

Participants self-selected to take part in this study, which may have led to a particular type of individual being recruited. Those who opted to take part may have had stronger views about CB. The CPs contacted me directly to express interest. In the case of the referrers, two participants agreed after being identified by their managers as being appropriate. I was aware that these participants may be different from the others, perhaps having less interest in CB or motivation to take part. I ensured they knew of their right to withdraw at any point. One of these participants expressed, what could be seen as quite outdated views on CB that were not shared by others. He identified that he had not had any training on the topic of CB, in over 15 years, which could have skewed the data, as all of the other referrers described having fairly recent training. As such, the findings may not represent the beliefs and understandings of all referrers and CPs working with this client group. Despite this, participants with a wide range of views but with overlapping ideas were recruited, so this did not appear to confound the findings.

In terms of demographics in the CP group, all but one participant was female, which is probably representative of the population of CPs. There was heterogeneity in the participants' cultural backgrounds and levels of experience. Conversely, in the referrer group, all but one participant was male. Similarly, there was heterogeneity in terms of cultural background and levels of experience. Many of the participants had a lot of experience in the field. There would inevitably be differences between those who started working in the field 25 years ago, compared to those who started two years ago, due to changes in guidance, societal attitudes and personal ideas resulting from experience. This did not appear to raise any differences large enough to cause sample bias.

Another important point is that the voice of the person who receives the label of CB is noticeably absent in this study. There is a lack of research looking to the voice of PWLD's, particularly people without the use of speech (Boxall & Ralph, 2011), as is often the case where CB is labelled. PWLD do not usually know they have been given the label of CB, and would not necessarily identify the 'issue' as a problem for themselves. For the purposes of exploring this construct, it was important to look to the voices of those who are viewing the challenge. This is not to say that research that looks to the inner world of this group is not important. As discussed in section 4.4 there are possible future research ideas that could pay closer attention to PWLD's own understanding of behaviour.

4.6. Researcher Reflexivity

As a researcher, my experience of the world is influenced by my assumptions, intentions and actions, and these factors might impact on the research process (Yardley, 2000). It is impossible to separate research from the researcher, so I will seek to make this relationship as transparent as possible, by sharing reflective thoughts on the process.

4.6.1. Epistemological Reflexivity

Adopting a critical realist perspective, meant that where I have offered links to theory, this should be seen as different ways of making sense of the concept, rather than making a claim about the "truth". I did not feel the necessity to

analyse and interpret the data from just one theoretical viewpoint. Taking a purely social constructionist stance would have allowed for more focus on discourse and interpretation, but I felt it was important to acknowledge there is a social reality in the service organisation dynamic between support services and CLDTs.

4.6.2. Methodological Reflexivity

Qualitative research can be critiqued due to small sample sizes and researcher bias and due to personal interpretation of themes (Willig, 2013), however, it also can provide in depth accounts of data and unexpected insights (Braun & Clarke, 2006). This study did not aim to achieve generalisation of findings but an understanding of complex phenomena (Willig, 2013). The method of TA enabled an analysis of a large amount of information. Whilst this felt somewhat overwhelming at times, this in depth immersion in the data left me with a genuine sense of admiration for the people who choose to work in the field of LD, and specifically CB. From experience, I have noticed it can be seen as a less desirable area of work, and it touched me to hear so many participants talk with such passion and feeling for the work and the people they support.

In terms of considering possible alternative methodologies, whilst there were many commonalities between the understanding of the referrers and CPs, using an IPA approach may have enabled the different and unique experiences of referrers and CPs in their roles, to be illustrated. Alternatively, grounded theory could have offered a useful analytical model, as it would allow for a theory to be developed about the interaction between CLDTs and support services, in terms of how CB is constructed. In a different vein, participants spoke about challenges of having a taken for granted definition and label for something that is not easily defined, and a struggle to find the right words. The social discourses at play might benefit from further examination that could be explored with discourse analysis. Analysing the naturally occurring language within both groups about the people they support, could provide valuable insights into the socio-psychological construction of CB within staff members who support people given this label.

The analysis conducted within this research is just one interpretation of the data, and it has been influenced by my own values and beliefs throughout each stage in the process.

4.6.3. Personal Reflexivity

It has been important to reflect on my own experiences and motivations that led me to be interested in this topic (Yardley, 2000). I have worked in the field of LD for a total of four years as a support worker and as an assistant and trainee psychologist. Most of my beliefs around CB developed through experience as an assistant psychologist. Due to this, I believe I was more aligned with the CP group, but knowing this was important, as it enabled me to reflect on feelings that arose for me in the process.

I understand CB to be a socially constructed concept. It is not internal, nor does it belong to a person. I understand it as a communication of an internal state, such as an emotion. I understand that the label can be helpful for services in terms of offering evidence based interventions. I also, however, see it as potentially unhelpful for the individual, as I have seen how easily labels become stuck to people, and how difficult it is for others to see beyond these labels. I made sure to bracket my views aside at the start of the process. I hope this enabled me to follow up points in an equally curious way throughout. Despite this, there may have been some interviews where I followed up ideas less because of an assumed understanding, or followed up more if it was a stance I was less familiar with.

4.6.3.1. Power: This was something I thought about throughout the process. Hutchinson, Wilson and Skodol Wilson (1994) described how taking part in interview research can offer a voice to the disenfranchised. One of the referrers spoke explicitly about wanting his voice and opinions to be heard by wider professionals. It seemed that some of the referrer participants used the interview to voice some of the frustrations working alongside CLDTs, which is perhaps something they feel unable to do in their usual context. Conversely other referrer participants appeared to use the interview to positively feedback about psychology. Power may have influenced this due to my visible role as a

psychologist and being in a perceived position to approve or disapprove of those views. I tried to level this power imbalance by reiterating my position as one of open minded curiosity.

I wondered if the CP participants identified similarities between us, due to our training and shared interest in the field of LD. This may have helped them to speak freely as there was likely an expectation that some of the ideas would be met with a shared understanding. With this comes the risk of assumed shared understanding, as discussed.

Throughout the analysis stage of the study, I remained aware how my position might influence how the data was interpreted. I read back over notes I had written after each interview, to remind me of any thoughts or biases I had.

4.6.3.2. Language: This research aimed to explore how CB is constructed in as much of a value-free way as possible. The title of the study and information sheet used the term CB, as it is currently the most widely used term within services. This was also confirmed as being the term that best fit, following the pilot interviews. I was aware that participants might identify more or less with this term, and so I made it clear at the beginning of each interview that there are many ways of thinking about it, and the idea of the interview is to explore that. I was aware that if I spoke about CB in a different way, for example, 'behaviour that challenges others' or even referred to it as a label, I could be leading participants to talk about it in a certain way, and this may have stifled alternate ways of thinking.

Despite this rationale, I have had an uncomfortable relationship with the term CB throughout the study and the write up. I found myself wanting to change the language in the write up, for example, to 'person labelled with CB'. I was keen not to fall into the pattern of referring to it as a taken for granted concept, as in my view this is highly contestable. Using a common term like this comes with many assumptions that have been created by the society in which it derived, such as individualising and blaming discourses. I ensured that the interview questions were framed in a way that did not close down different ways of talking about the

construct of CB. Although I may not have agreed with some of the perspectives shared in the research, I do not think this hindered my analysis, as considering how differences emerge within systems, was at the core of my research.

4.7. Evaluation of Research

There are multiple ways to evaluate and review qualitative research and in an effort to highlight the validity of these findings, Yardley's (2000) four principles are evaluated.

4.7.1. Sensitivity to Context

Research should be contextualised in relation to relevant theory and literature. I conducted a literature search of how CB is constructed from different perspectives that informed my thinking, alongside my ideas from experience in the field of LD. Although I considered the impact of power and emotion in my literature review, I did not anticipant how integral these ideas were in the construction of CB in my interpretation. Thus further research was drawn out in the discussion, as is consistent with the inductive part of this research (Braun & Clarke, 2006).

It is also necessary that there is sensitivity to the participants' perspectives and the socio-cultural context they are within. The participants were asked open-ended questions, to encourage them to talk about the issues important to them on the topic of CB. During the analysis of my data, it was imperative that I remain sensitive to how the socio-cultural context shapes the way the participants talked about the topic. This was particularly true because I interviewed two groups from different contexts and so professional identity inevitably had an influence on the findings. Having some experience within both groups enabled me to offer different interpretations.

4.7.2. Commitment and Rigour

Commitment to the research can be shown through thorough data collection, breadth and depth of data analysis, methodological competence and immersion

in the topic (Yardley, 2000). This was my first encounter with qualitative research, and my skills in TA have grown throughout the process of teaching, reading and thinking critically about it. A sample is considered adequate when theoretical saturation is reached and new data is not generating new ideas (Oppong, 2013). This had to be balanced against the time and resources I had to recruit, so there may have been further avenues to explore. I would say that both groups reached saturation, in particular the CP group, in that many similar ideas were arising. I would tentatively say that this sample represents a population of staff who have an interest in the field of CB.

I was on placement in a LD service whilst collecting my data, which also helped me to engage with the topic from a clinical perspective, outside of the research frame. I had a sufficient amount of time to fully immerse myself in the data, with initial familiarisation and several weeks of initial and refined coding, before interpreting the themes. The process of triangulation is complicated in qualitative research, especially when a critical realist stance is taken, as the aim is not to search for a knowable 'truth' (Braun & Clarke, 2006). To achieve this, the findings were compared to the research literature. Credibility was assessed via my supervisor checking the initial codes, themes and draft chapters.

4.7.3. Transparency and Coherence

There is a need to be transparent in the methods and description of the data collected, to investigate the fit between the research question, the theoretical framework and the methods. To highlight this, I have included examples of each stage of the analysis, such as examples of coded transcripts, the list of initial codes and the initial themes that were highlighted (see appendices I-O). This gives a coherent story of how I came to the analysis and interpretations that I have presented. It is hoped the data has been presented in a way that aims to give a convincing argument about the interpretation.

4.7.4. Impact and Importance

This can be assessed in relation to the objectives of the analysis, how it was intended to be applied and for whom the results are deemed relevant (Yardley, 2000). The theoretical, practical and socio-cultural implications will be outlined in

section 4.8. This study is of clinical relevance to people labelled with CB and their support networks, due to the potential service implications. I will make every effort to disseminate the findings to the participants and wider academic forums.

4.8. Wider Implications of Research

The implications of this study could be considered using Bronfenbrenner's (1979) ecological systems theory. The impact could be considered on the individual level, microsystem (service level), exosystem (policy level) through to the macrosystem (society).

4.8.1. Individual and Service Level Implications

The main implications of these findings are around the focus on relationships, emotions and power and the role CP's can take in considering these. There might be shared understandings within networks, but if attention isn't paid to relationships and emotions and a levelling of power, a move towards a greater well-being for the client may be very hard to achieve. In an ideal world the following ideas should be considered within services:

- Building and fostering the human element of relationships between staff and clients. This includes supporting staff to mentalise the pain and distress a client may be in, and being able to bear witness and sit with it. This requires a shift in service ethos, where consistent space for reflection is prioritised.
- Training for support staff should focus equally on practical techniques and relationships, for example, what does it feel like to relate to a person in distress. Creating stories of hope, acceptance and empowerment for clients.
- Training on the history of language and the social construction of CB, rather than it being a taken for granted concept. Many people already hold these beliefs, so having open forums to discuss these ideas could have a positive impact on creating an empowering and human-focused service ethos.

- Collaborative working between CLDT's and support services. There is a need for something that levels the power relationships between services, where staff work alongside each other in a genuine and cohesive way. This could take ideas from the 'flexible response model', as suggested by Carnaby et al, (2011).

- Consideration of whether the referral dynamic between support services and CP's should continue to exist, if it just serves to reinforce the same discourses about behaviour? CPs can offer specialist support in terms of relational and systemic working, so perhaps the shift needs to occur in how referrals are made, instead of being for an individual client, being for a specific challenge the staff team are having.

4.8.2. Policy Level Implications

A significant factor in the service level implications is funding and resources. Many of these ideas suggested, are in line with what services would like to be doing more of, if the resource was available to them. Services are often funded on the basis of offering specialist support to those with complex needs. Without the label of CB, there needs to be shifts in how services are funded. There needs to be changes whereby the behavioural work is still valued, but there is equal emphasis on relationships and emotion management.

I also wonder if some of these ideas could apply to other settings whereby communication or distress might be constructed as CB, for example people diagnosed with dementia.

4.8.3. Societal Level Implications

On a wider societal level, there needs to be the consideration of the impact of language. If we continue to use dehumanising labels to describe a person, marginalising discourses will be maintained. We know that relationships are hugely important to PWLD, and by using these ways of thinking about something, we risk further segregating people from the communities in which they live and exist. I would argue that CB is everybody's concern, and shouldn't be the domain of 'experts in disability' only.

4.9. Conclusions

When I initially started interpreting the data, I was left feeling confused, in that many of the understandings of CB seemed to be shared between the group, yet still a schism exists between services. I therefore had to move beyond 'understandings'. It was only when I started to pay more attention to themes of power and emotion that I realised these really underpinned everything else. In some ways I was replicating what services find themselves doing, paying attention or 'lip service' to emotion and power as something important to talk about, but not raising it as a priority above all else.

In conclusion, it is hypothesised that the differences and disagreements that can arise between services, are possibly not because of different interpretations of CB, but because of a lack of attention on emotions, relationships and power. These concepts are suggested to be central to how services support PWLD. Therefore I would propose that these ideas should be more prioritised within services, with an emphasis on human connection across the whole network.

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APPENDICES

Appendix A: Email to special interest LD group for clinical psychologist recruitment

Hi All,

I am a second year trainee at UEL currently in the process of trying to recruit for my thesis. Some of you who attended the June SIG meeting may remember me briefly presenting my research idea there and it was kindly agreed that I could email SIG members to see if anyone would be interested in taking part.

The title of my project is 'Exploring understandings of "challenging behaviour" in the context of People with Learning Disabilities: views of those who refer and those who respond'. I'm looking to interview clinical psychologists and those who make referrals to psychology teams (i.e. day services, respite services) about their views and understandings of challenging behaviour and the interventions that are used. The interviews will take between 1-1.5 hours and I can be flexible with dates/times at present. I also want to make it as easy as possible to take part, so would be happy to come to your work place if there is space for interviewing there or at another preferred location, or if there is no suitable space, we can discuss further.

I am attaching the information sheet for the project as well, for further details. If anyone is interested in taking part I would be very grateful, or if you have any further questions, I would invite you to contact me directly at

████████████████

Thank you very much,

Jess Walsh

Trainee Clinical Psychologist

INFORMATION SHEET

The Principal Investigator(s)

Jessica Walsh

Contact Details: ███████████████████████

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in a research study. The study is being conducted as part of my Professional Doctorate in Clinical Psychology at the University of East London.

Project Title

Exploring understandings of "challenging behaviour" in the context of People with Learning Disabilities: views of those who refer and those who respond.

Project Description

This project aims to explore how those who work with people with learning disabilities make sense of "challenging behaviour". You will be invited to attend an interview with Jessica Walsh (researcher) that will take between 1-1.5 hours. Within this interview you will be asked about referrals you have been involved in for "challenging behaviour" and your thoughts/feelings about the referrals. I will be interviewing individuals who have made referrals to CLDTs (day services or respite) and individuals who have responded to referrals (clinical psychologists). The interviews will be semi-structured so the questions will vary depending on what comes up in each interview. The interview will be recorded with an audio recorder and will be transcribed by the researcher. The finished research will be presented in the form of an academic thesis. After the project has been submitted

and examined the researcher plans to write it up for submission to a psychology journal.

There are no likely risks or dangers involved in taking part in this study. However, it is possible you could get upset if you were talking about something you had found difficult or emotional. Should this happen you are welcome to take a break at any time in the interview or decide to finish it at another time. If you feel you require further support after the interview has finished, options for this can be discussed with the researcher at the time or using the contact details provided.

Inclusion/exclusion criteria

The only inclusion criteria is that you must have made *(referrers from day/respite services)* or responded to *(clinical psychologists)* a referral to the CLDT for an individual displaying "challenging behaviour" in the last year.

Confidentiality of the Data

Each interview will be recorded on an audio recorder belonging to the researcher. Only the researcher will listen to the recordings when typing them into transcripts. You will be asked not to mention any names of people, services or other identifiable information during the interview. Any names that are mentioned, including your own and any other information that would make you or someone else identifiable will be altered in the transcript. The typed transcript of the interview may be read by the researcher's supervisor at the University of East London and by the examiners who test the researcher when the project is assessed. No one else will have access to the transcript. The audio file and transcript will be saved on a computer and USB that is password protected. The final write up of the research will include a small number of quotes from interviews, none of which will have identifying information in. The audio recordings and written transcripts will be kept as a password protected computer file for five years and might be used for additional articles or publications based on the research.

The researcher has a responsibility to consider the safety of the people who take part in the study. If any concerns are raised about the safety or well-being of yourself or others the researcher is legally required to inform someone who may

be able to help or may need to know. The researcher would endeavour to discuss this with you first and then discuss with the study supervisor Dr Jenny Jim.

Location

Interviews will take place at your place of work, but if other places are preferred, this can be discussed and considered.

Disclaimer

You are not obliged to take part in this study and should not feel coerced. You are free to withdraw at any time. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason. If you do withdraw you will be asked for your reasons for doing so, but you are not obliged to answer this.

Please feel free to ask any questions. If you are happy to take part you will be asked to sign a consent form prior to your participation. Please retain this invitation letter for reference.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor, Dr Jenny Jim, School of Psychology, University of East London, Water Lane, London E15 4LZ.

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ.

Thank you in anticipation.

Yours sincerely,

Jessica Walsh [August 2015]

Appendix C: Example of email to day services for referrer recruitment

Hi █████,

I'm a trainee clinical psychologist, from the University of East London. I'm in the
process of recruiting for my final year thesis project. The title is 'Exploring
understandings of "challenging behaviour" in the context of People with
Learning Disabilities: views of those who refer and those who respond'. I'm
interested in interviewing psychologists and those who make referrals to
psychology teams (i.e. day services, respite services) about their views
and understandings of challenging behaviour and the interventions that
are used.

█████████████, Clinical Psychologist from ██ █████ is supporting me with
recruitment and passed me your details. I was hoping that it would be
possible to perhaps attend a staff meeting at █████████ or perhaps meet
a few members of the team, just to give a brief overview of the project,
leave some information sheets and then if anyone was interested in taking
part they could contact me directly.

Is this something you think might be possible?

Thank you and best wishes,

Jess Walsh

Trainee Clinical Psychologist

University of East London

Appendix D: Ethics review decision

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational
        Psychology

SUPERVISOR: Jenny Jim   **REVIEWER: Kenneth Gannon**

STUDENT: Jessica Walsh

Title of proposed study: Exploring understandings of "challenging behaviour" in
the context of People with Learning Disabilities: views of those who refer and
those who respond
Course: Professional Doctorate in Clinical Psychology

DECISION *(Delete as necessary)***:**

*APPROVED

APPROVED: Ethics approval for the above named research study has been
granted from the date of approval (see end of this notice) to the date it is submitted
for assessment/examination.

**APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED <u>BEFORE</u> THE
RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this
circumstance, re-submission of an ethics application is <u>not</u> required but the student
must confirm with their supervisor that all minor amendments have been made
<u>before</u> the research commences. Students are to do this by filling in the
confirmation box below when all amendments have been attended to and emailing
a copy of this decision notice to her/his supervisor for their records. The supervisor
will then forward the student's confirmation to the School for its records.

NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED
(see Major Amendments box below)**:** In this circumstance, a revised ethics
application must be submitted and approved before any research takes place. The
revised application will be reviewed by the same reviewer. If in doubt, students
should ask their supervisor for support in revising their ethics application.

Minor amendments required *(for reviewer)*:

Major amendments required *(for reviewer):*

111

Confirmation of making the above minor amendments *(for students)*:

No amendments required
Student's name *(Typed name to act as signature):*   Jessica Walsh
Student number: u1331820
Date: 01/05/2015

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

If the proposed research could expose the <u>researcher</u> to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

HIGH ☐

MEDIUM ☐

LOW ☒ x

Reviewer comments in relation to researcher risk (if any):

Reviewer *(Typed name to act as signature)*:   *Kenneth Gannon*

Date: May 1st 2015

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee (moderator of School ethics approvals)

PLEASE NOTE:

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, travel approval from UEL (not the School of Psychology) must be gained if a researcher intends to travel overseas to collect data, even if this involves the researcher travelling to his/her home country to conduct the research. Application details can be found here: http://www.uel.ac.uk/gradschool/ethics/fieldwork/

Appendix E: Consent form for all participants

CONSENT FORM

Consent to participate in a research study

Exploring understandings of "challenging behaviour" in people with learning disabilities: views of those who refer and those who respond.

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed, and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study that has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself. If I do withdraw I understand I will be asked why, so that this can be recorded in the research write up, but I am not obliged to provide an answer.

Participant's Name (BLOCK CAPITALS)

………………………………………………………………………………….

Participant's Signature

…………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

…………………………………………………………………………………..

Researcher's Signature

……………………………………………………………………………………

Date: …………………..………

Appendix F: Interview schedules for referrers and clinical psychologists

Interview for referrers

Thank you for agreeing to participate in this study.

As you know I am interested in your understandings of what you classify as "challenging behaviour". I will use this term throughout the interview, as it is a term often used within services for people with learning disabilities, but I understand there may be different ways of understanding it, which the interview will explore. Before we start as I will be asking about specific work you have carried out with service users, please can I ask you either avoid using names of people/names of services or any other identifying information or use a pseudonym for confidentiality reasons. In addition, this information will be changed when transcribing as well.

1. Can I start by asking what led you to want to take part in this research? (Prompt- is there anything important or particularly interesting to you about the topic?)
2. What does the term "challenging behaviour" mean to you?
3. Where do you think that understanding has come from?
4. What kind of behaviours/experiences would come under the term "challenging behaviour" in your view?
5. What kind of things do you consider when making a referral for "challenging behaviour" to the CLDT? [Prompts - how do you consider; timing of referral, who to request involvement from?]
6. How does your team think about when multiple referrals for "challenging behaviour" have been made across a person's lifespan? [Prompts- how does it affect expectations, what is requested?]
7. Can you tell me a bit about a recent referral you made for "challenging behaviour", ideally where an intervention has begun or has been completed (please avoid using identifiable information where possible)? (Prompt- what was observed or reported, how did it come to be understood as being "challenging behaviour" and not something else?)
8. What stories/events led up to this referral to the CLDT being made?

9. What thoughts/feelings did you and/or the team have when considering making the referral?

10. What were your initial ideas about what was happening for the individual?

11. What thoughts/feelings do you imagine the CLDT may have had when reading the referral?

12. How much did the person referred know about the referral?

      a. If nothing, was there something that stopped you from discussing it directly with then?

      b. If the person referred knew about the referral, what were their hopes/expectations for it? If not, what did you imagine their hopes/expectations would be?

13. What were your hopes/expectations for the referral outcome?

14. Following any assessment, what further ideas did you have about why the person was displaying "challenging behaviour".

15. What intervention was carried out or planned to carry out?

16. What has been the outcome of this work (so far)? Are the CLDT still involved with the person?

17. Did this piece of work impact on how you view "challenging behaviour" and your approach to the work, if so how?

18. Can you tell me about any other past experiences of working with the CLDT specifically around "challenging behaviour" where you felt there was a different outcome? [Prompts- do you have any thoughts/reflections about this piece of work? How has it impacted on future work you've carried out?]

19. Can you tell me your thoughts on the referral process or interaction between the CLDT and referrers- what already works? What could be improved?

20. Has your view of what "challenging behaviour" is changed over time? [Prompt- if so, what do you think contributed to or influenced this shift?]

21. If there were no pressures on time or resources, is there anything you would do differently in your work with people who have "challenging behaviours".

22. Thank you for sharing your thoughts on "challenging behaviour with me today, finally, is there anything we haven't talked about that you think might be relevant or you would like to share?

Interview for clinical psychologists

Thank you for agreeing to participate in this study.

As you know I am interested in your understandings of what you classify as "challenging behaviour". I will use this term throughout the interview, as it is a term often used within services for people with learning disabilities, but I understand there may be different ways of understanding it, which the interview will explore. Before we start as I will be asking about specific work you have carried out with service users, please can I ask you either avoid using names of people/names of services or any other identifying information or use a pseudonym for confidentiality reasons. In addition, this information will be changed when transcribing as well.

1. Can I start by asking what led you to want to take part in this research? (Prompt- is there anything important or particularly interesting to you about the topic?)

2. What does the term "challenging behaviour" mean to you?

3. Where do you think that understanding has come from?

4. What kind of behaviours/experiences would come under the term "challenging behaviour" in your view?

5. What things do you consider when receiving a referral for "challenging behaviour" [Prompts- how do you consider, who to involve, when to get involved, what the assessment should involve (how wide/deep)]

6. How does your team think about when multiple referrals for "challenging behaviour" have been made across a person's life span? [Prompts- how does it affect expectations/input offered?]

7. Can you tell me a bit about a recent referral you received for "challenging behaviour" ideally where an intervention has begun or has been completed (please avoid using identifiable information where possible) [Prompt- what was reported, how did it come to the team?]?

8. When thinking about that recent referral what do you think led up to the referral being made?

9. What thoughts/feelings did you and/or the team have when reading the referral?

10. Did you have any initial ideas about what was happening for the individual?

11. What thoughts/feeling do you think the team were having when they considered making the referral?

12. What hopes/expectations do you think the referrer (and the client if they were aware of referral) had for the referral?

13. Can you tell me about your approach in responding to this referral, how did you follow it up?

14. Following any assessment, what further ideas did you have about why the person was displaying "challenging behaviour".

15. What kind of intervention did you carry out/plan to carry out?

16. What has been the outcome to the work (so far?) Are you still involved with the person?

17. Did this piece of work impact on how you view "challenging behaviour" and your approach to the work, if so how?

18. Can you tell me about any other past experiences of receiving referrals for "challenging behaviour" where you felt there was a different outcome? [Prompts- do you have any further thoughts/reflections about this piece of work? How has it impacted on future work you've carried out?]

19. Can you tell me your thoughts on the referral process or interaction between the referrers and the CLDT- what already works? What could be improved?

20. Has your view of what "challenging behaviour" is changed at all over time? (Prompt- If so, what do you think contributed to or influenced the shift?)

21. If there were no pressures on time or resources, is there anything you would do differently in your work with people who have "challenging behaviours".

22. Thank you for sharing your thoughts on "challenging behaviour with me today, finally, is there anything we haven't talked about that you think might be relevant or you would like to share?

Appendix G: Initial demographic questions

Initial Questions (referrer)

- Gender
- Ethnicity
- Role within team
- Length of time in team
- Length of experience in the field (i.e. Learning Disability and/or challenging behaviour) and any previous positions held
- Estimate the amount of referrals you have made for 'challenging behaviour' in the last year
- Can you give some examples of the kinds of 'challenging behaviour' you have made referrals for in the past?
- Have you had any training specific to 'challenging behaviour'?

Initial Questions (CP)

- Gender
- Ethnicity
- Role within team
- Length of time in team
- Length of experience in the field (i.e. Learning Disability and/or challenging behaviour) and any previous positions held
- Estimate the amount of referrals you received as a team for 'challenging behaviour' in the last year
- Can you give some examples of the kinds of 'challenging behaviour' you have you received referrals for in the past?
- Have you had any training specific to 'challenging behaviour'?

Appendix H: Transcription Notation System (adapted from Braun & Clarke, 2013)

Feature	Notation and explanation
Identity of speaker	Speakers name, followed by colon (e.g. Sarah:) signals identity of speaker. Jess: is used for when interviewer is speaking. New line used every time a new speaker starts, first word of each new turn of talk in a capital letter.
Laughing	[laughter] signals laughing by person speaking
Pausing	[.] signals a pause that is significant but brief (i.e. a few seconds). [number] indicates a longer pause, e.g. [10] for 10 second pause
Spoken abbreviations	If someone speaks an abbreviation then it is transcribed, e.g. BPS for British Psychological Society, but it has not been abbreviated unless speaker did so.
Overlapping speech	((in overlap)) before overlapping speech
Brief interjections	If person says a brief interjection when other person is speaking, present in < >, for example 'I will ask you about your experiences of this <OK> before'
Inaudible speech	[inaudible] for speech and sounds that are completely inaudible. When some can be heard use single parentheses to indicate best guess, e.g. (ways of life)
Uncertainty about who is speaking	Use ? to signal uncertainty about the speaker

Non-verbal utterances	Render phonetically and consistently common non-verbal sounds uttered by participants e.g. 'erm' 'er' 'mm' 'mm-hm'.
Use of punctuation	Mindful use as can change meaning of spoken data.
Reported speech	When a person provides an apparent verbatim account of the speech or thoughts of another person (or their own past speech). Signal using inverted commas e.g. and she said 'I don't know what to think'.
Names of media e.g. TV programmes	Presented in italics
Identifying information	Provide unmarked, appropriate alternatives to potentially identifiable information.

Appendix I: Example of annotated referrer transcript excerpt

93   Jess: How would you think about kind of who to request

94   involvement from? So like different members of the team

95   how do you think about that?

96   Charlie: You mean of the [CLDT] team?

97   Jess: Yea

98   Charlie: Firstly I probably wouldn't give so much thought

99   to that, again it's probably more down to [manager] to

100 know what is the best channel for it, um yea no.

Direct workers less power over where referral goes

101 Jess: OK, and you mentioned about kind of people

102 maybe coming back into the service and I was going to

103 ask you about that as well. How does your team think

104 about when multiple referrals are made for challenging

105 behaviour across a person's life span, so kind of does it

106 impact on expectations of a piece of work, or what, how

107 do you think about it as a team, when someone's been

108 referred several times to [CLDT]?

109 Charlie: Well recently I had a somewhat frustrating feeling

110 when I did the referral for one of the people that I key

111 work around sexualised behaviour and I was looking back

112 through the documentation, almost for like a good ten

113 years and I could see the same issue being discussed

frustration of same issues being discussed over the years

114 again and again, I couldn't see from the paper work

115 specifically that [CLDT] as such was involved, I would

116 assume that at some time it might well have been

117 referred um, it just looked to me like there wasn't like sort

118 of a very good track of the kinds of discussions that were,

No clear history taking of previous interactions

119 that came up in the past and that as the staff team

120 changed, which happens inevitably, you know like every

Staff teams change - history gets forgotten

121 few years or so, then new people will come in and you

122 will deal with again exactly the same problem and you will

123 go through the same process of you know having the

124 same conversations, but that was, I actually had quite a

Repeated conversations nothing moves on/ changes

121

Appendix J: Example of annotated CP transcript excerpt

29 Jess: So is there anything particularly interesting to you

30 about the topic?

[margin right: Lack of understanding from referrers about CB]
[margin right: There is a 'right' way of understanding CB]

31 Kim: So I guess our big challenge really is helping people

32 really understand what challenging behaviour is, so, we

[margin left: High proportion of CB referrals]

33 get loads of referrals for challenging behaviour, more

34 than a third of our referrals across the year are for

35 challenging behaviour and I would say actually only a tiny

[margin right: Inappropriate referrals]

36 proportion of those are for what I would call challenging

37 behaviour. So that's part of the work we're trying to do

[margin left: Teaching referrers as intervention.]

38 here, trying to educate people about that, but also think

39 about how we respond as there's no point responding all

[margin right: Risk of using resource intense approach when not needed]

40 guns blazing PBS for each referral, because actually only

[margin left: Tendency to give big response to small 'problem' in CB]

41 a small proportion really need that response.

42 Jess: Ok so moving on nicely I guess to what does the

43 term challenging behaviour mean to you?

44 Kim: Yea so I suppose for me it's more thinking about the

[margin right: - Behaviour is on a spectrum]

45 individuals at the more severe end of the behaviour

[margin right: - To be challenging it should be severe]

46 spectrum, so people who are really struggling to engage

47 in the community because of their behaviour, whether

[margin left: Reduction in community engagement.]

48 that's self-harm, harm to others, damage to property,

[margin right: Risk behaviour]

49 where it's really impacting on their quality of life, so

[margin right: Reduction in quality of life]

50 generally we would expect that to be people with more

51 severe learning disability or autism, that client group, so

[margin left: CB more likely in severe LD group than mild.]

52 that's how I see it, but yea as I say that term is now being

[margin right: Shift in understanding in services.]

53 used for anyone who's a bit different I think, so that's

[margin right: Not conforming to social norms - CB]

54 where some of the difficulty lies in terms of how we

55 respond to referrals.

Appendix K: Table of initial codes- referrers and clinical psychologists

Initial codes- referrers	Initial codes- CP
1. Fear felt by staff in relation to CB 2. Staff feeling stressed/distressed in relation to CB 3. Other emotions felt by staff in relation to CB 4. Importance of reflective space 5. Importance of emotional support for staff 6. Impact of staff emotions on the relationship between staff and client 7. Benefits of a calm/relaxed approach 8. Use of reactive strategies 9. Lack of proactive support 10. Use of proactive strategies/action 11. Differences in view of the problem in the system 12. Disagreements with psychology –not enough time spent 13. Disagreements with psychology- they don't understand what it's like 14. Disagreements with psychology- intervention 15. Feeling as though being 'done to'/not collaborative 16. Desire to receive more guidance/be told what to do 17. Challenges of talking about difference in the system 18. Lack of consistency- Staff teams changing 19. Collaborative working between CLDT and whole network 20. Consistency is the goal 21. Inconsistency causes CB 22. Physical/medical issues interpreted as CB	1. Fear in network in relation to CB 2. Feelings of upset/distress in support workers in relation to CB 3. Other emotions linked to CB 4. CLDT anxiety 5. Frustration associated with CB 6. Big emotional impact working in the field 7. Importance of reflective space 8. Ongoing support for staff 9. Link between staff and clients feelings 10. Fear of blame in the network 11. Preference towards preventative work- general training/workshops 12. Preference towards preventative work- before a crisis occurs 13. Pressure for quick responses to referrals 14. Crisis support/reactive responses 15. Support staff tendency to use reactive strategies 16. Referrals made for guidance/advice 17. Different views of the problem in the system 18. Ensuring views of all network are heard 19. Network not wanting external input 20. Different goals/expectations for making a referral in network 21. Goal of network- to remove behaviour 22. Frequent inappropriate referrals 23. Assumptions made about systems/individuals 24. Importance of consistent team work 25. Importance of good relationships in the network 26. Problems when network is not consistent/robust 27. Positive impact of effective collaboration

23. Having an opinion/ expressing dislike interpreted as CB	28. Lack of understanding leading to inappropriate referrals
24. Sensory needs interpreted as CB	29. When it impacts on wider community- constructed as CB
25. Other things interpreted as CB	30. Not conforming to societal expectations constructed as CB
26. Normalising of CB	31. Expressing dislike constructed as CB
27. Individuals don't have clear histories	32. Physical health problems constructed as CB
28. A full history of clients life is important	33. Psychology resource precious
29. Environmental influences on behaviour	34. Basic involvement only needed- not specialist- frustrating
30. CB as having no cause	35. Interpersonal difficulties constructed as CB
31. CB being a challenge to others	36. Sexual behaviour constructed as CB
32. CB being a long term, pervasive issue	37. Teams causing CB by their own behaviour
33. Services get into cyclical patterns of managing CB	38. CB as sensory issue
	39. Some CB is normal
34. Clients developing reputation due to beliefs about CB/stigma	40. Other issues interpreted as CB- multiple hypotheses
35. Impact of risk and CB	41. Impact of structure in environment
36. Behaviour communicating an emotional state	42. Importance of having a good client history
37. Two-way communication issue- not making self understood/not being understood	43. Importance of appropriate environments
38. CB is about communication- narrative	44. CB perceived as having no cause by referrers
39. CB as social construction	45. CB being a challenge to others
40. Support workers having less power in a system	46. Some people/teams require indefinite support- permanency of CB
41. Challenges of making changes across network- power	47. Re-referrals for same/different problem
42. CLDT as holders of power in system	48. People with CB get reputations
43. Disempowering effect of CB on support teams	49. Impact of risk and CB
44. CB as severe	50. CB as communication of emotions/needs
45. CB as a spectrum	51. Behaviour is communication of emotional state
46. CB resulting in exclusion from community	52. Behaviour is communication- narrative
47. CB as bad/naughty behaviour	53. CB as social construction
48. CB as not deliberate	54. CLDTs not having power to make change in services
49. CB as positive	55. Support teams not feeling empowered
50. Stigma associated with CB	56. CLDT holding power in the network

51. Complexity of CB	57. Clients hold least amount of power
52. Searching for cause/reason for CB	58. Effect of powerful discourses on frontline staff
53. Understanding comes from experience	59. Dominant definitions of CB
54. Need for multi-faceted intervention	60. CB about reduction in quality of life
55. People change over time	61. CB relates to access to community life
56. Challenges of discussing with the individual	62. CB as severe
57. Help seeking beliefs	63. Responsibility taking
58. Goals- to remove behaviour	64. Those observing the behaviour should make the referral
59. Goals- independence, quality of life	65. Importance of referrers taking responsibility for the intervention
60. Support worker creativity/curiosity	66. Sharing the burden of CB by referral making
61. Outdated understandings/interventions	67. People as behaviours
62. Client's needs as priority	68. Complexity of CB
63. Other priorities taking over	69. Impact on policy/guidance on understanding
	70. Only writing guidelines no longer appropriate
	71. Developmental perspective to CB
	72. Looking for causes of behaviour
	73. Graded approach to intervention
	74. Psychology in more overseeing role
	75. Too much pressure- not enough time/resource
	76. Gaps in services identified
	77. Challenges/opportunities of working on individual level
	78. Importance of keeping open minded, non-reductionist stance
	79. Other priorities taking over
	80. Outcomes in CB work are mixed

Appendix L: Table of refined codes and initial themes

Refined codes and initial themes- referrers	Refined codes and initial themes- CPs
1. Emotions felt in relation to CB a. *Fear felt by staff in relation to CB* b. *Staff feeling stressed/distressed in relation to CB* c. *Other emotions felt by staff in relation to CB* d. *Importance of reflective space* e. *Importance of emotional support for staff* f. *Impact of staff emotions on the relationship between staff and client* g. *Benefits of a calm/relaxed approach* **2. Reactive vs proactive response** a. *Use of reactive strategies* b. *Lack of proactive support* c. *Use of proactive strategies/action* **3. Differences of understanding in system** a. *Different views of the problem in the system* b. *Disagreements with psychology – not enough time spent* c. *Disagreements with psychology- they don't understand* d. *Disagreements with psychology- intervention* e. *Feeling as though being 'done to'/not collaborative* f. *Desire to receive more guidance/be told what to do* g. *Challenges of talking about difference in the system* **4. Importance of good relationships in network- consistency** a. *Lack of consistency- Staff teams changing* b. *Collaborative working between CLDT and whole network* c. *Consistency is the goal* d. *Inconsistency causes CB* **5. Other issues interpreted as CB** a. *Physical/medical issues interpreted as CB*	**1. Emotions felt in relation to CB** a. *Fear in network in relation to CB* b. *Feelings of upset/distress in support workers* c. *Other emotions linked to CB felt by staff* d. *CLDT anxiety* e. *Frustration associated with CB* f. *Big emotional impact working in the field* g. *Importance of reflective support for staff* h. *Link between staff and clients feelings* i. *Fear of blame in the network* **2. Reactive vs proactive response** a. *Preference towards preventative work- general training/workshops* b. *Preference towards preventative work- before a crisis occurs* c. *Pressure for quick responses to referrals* d. *Crisis support/reactive responses* e. *Support staff tendency to use reactive strategies* f. *Referrals made for guidance/advice* **3. Differences of understanding in system** a. *Different views of the problem in the system* b. *Ensuring views of all network are heard* c. *Network not wanting external input* d. *Different goals/expectations for making a referral in network* e. *Goal of network- to remove behaviour* f. *Frequent inappropriate referrals* g. *Assumptions made about systems/individuals* **4. Importance of good relationships in network** a. *Importance of consistent team work* b. *Importance of good relationships in the network* c. *Problems when network is not consistent/robust*

b. *Having an opinion/expressing dislike interpreted as CB*

c. *Sensory needs interpreted as CB*

d. *Other things interpreted as CB*

e. *Normalising of CB*

6. Impact of context/history/environment on CB

a. *Individuals don't have clear histories*

b. *A full history of clients life is important*

c. *Environmental influences on behaviour*

7. CB as having no cause

8. CB being a challenge to others

9. Long term cyclical nature of CB

a. *CB being a long term, pervasive issue*

b. *Services get into cyclical patterns of managing CB*

c. *Clients developing reputation due to beliefs about CB/stigma*

10. Impact of risk and CB

11. CB as communication

a. *Behaviour is communication of emotional state*

b. *Two-way communication issue- not making self understood/not being understood*

c. *Behaviour is communication- narrative*

12. CB as social construction

13. Power in networks

a. *Support workers having less power in a system*

b. *Challenges of making changes across network- power*

c. *CLDT as holders of power in system*

d. *Disempowering effect of CB on support teams*

14. Dominant definitions of CB

a. *CB as severe*

b. *CB as a spectrum*

c. *CB resulting in exclusion from community*

d. *CB as bad/naughty behaviour*

e. *CB as not deliberate*

f. *CB as positive*

d. *Positive impact of effective collaboration*

5. Other issues interpreted as CB

a. *Lack of understanding leading to inappropriate referrals*

b. *When it impacts on wider community- constructed as CB*

c. *Not conforming to societal expectations constructed as CB*

d. *Expressing dislike constructed as CB*

e. *Physical health problems constructed as CB*

f. *Psychology resource precious*

g. *Basic involvement only needed- not specialist- frustrating*

h. *Interpersonal difficulties constructed as CB*

i. *Sexual behaviour constructed as CB*

j. *Teams causing CB by their own behaviour*

k. *CB as sensory issue*

l. *Some CB is normal*

m. *Other issues interpreted as CB- multiple hypotheses*

6. Impact of context/history/environment on CB

a. *Impact of structure in environment*

b. *Importance of having a good client history*

c. *Importance of appropriate environments*

7. CB perceived as having no cause by referrers

8. CB being a challenge to others

9. Long term cyclical nature of CB

a. *Some people/teams require indefinite support- permanency of CB*

b. *Re-referrals for same/different problem*

c. *People with CB get reputations*

10. Impact of risk and CB

11. CB as communication

a. *Behaviour is communication of emotional state*

b. *Behaviour is communication- narrative*

12. CB as social construction

13. Power in networks

a. *CLDTs not having power to make change in services*

b. *Support teams not feeling empowered*

c. *CLDT holding power in the network*

g. *Stigma associated with CB*	d. *Clients hold least amount of power*
15. Complexity of CB	e. *Effect of powerful discourses on frontline staff*
16. Searching for cause/reason for CB	**14. Dominant definitions of CB**
17. Understanding comes from experience	a. *Dominant definitions*
18. Interventions	b. *CB about reduction in quality of life*
a. *Need for multi-faceted interventions*	c. *CB relates to access to community life*
b. *People change over time*	d. *CB as severe*
c. *Challenges of discussing with the individual*	**15. Responsibility taking**
d. *Help seeking beliefs*	a. *Those observing the behaviour should make the referral*
e. *Goals- to remove behaviour*	b. *Importance of referrers taking responsibility for the intervention*
f. *Goals- independence, quality of life*	c. *Sharing the burden of CB by referral making*
g. *Support worker creativity/curiosity*	**16. People as behaviours**
h. *Outdated understandings/interventions*	**17. Complexity of CB**
i. *Client's needs as priority*	**18. Impact on policy/guidance on understanding**
j. *Other priorities taking over*	**19. Interventions**
	a. *Only writing guidelines no longer appropriate*
	b. *Developmental perspective to CB*
	c. *Looking for causes of behaviour*
	d. *Graded approach to intervention*
	e. *Psychology in more overseeing role*
	f. *Too much pressure- not enough time/resource*
	g. *Gaps in services identified*
	h. *Challenges/opportunities of working on individual level*
	i. *Importance of keeping open minded, non-reductionist stance*
	j. *Other priorities taking over*
	h. *Outcomes in CB work are mixed*

Appendix M: Example of quotes relating to codes

Clinical Psychologists

1. Emotions felt in relation to CB
a. Fear in network in relation to CB
Kim/ 85 "because people won't take her out"   **Kim/ 98** "staff are wary about taking people out, so it really restricts their community access"   **Annabel/ 377** "She felt nervous going out with him."   **Annabel/ 576** "the GP was too afraid because he just said well it's impossible to do an annual health check with him"   **Sandy/ 221** "tried to move him back to the borough and given the costs, there were cost implications. But there was a big worry because he was, he presented with significant challenging behaviour"   **Sandy/ 247** "they were very cautious, very worried that they were not going to cope"   **Sandy/ 295** "they did not have enough skills or support to manage his presentation and that he was constantly agg…presenting with challenging, behaviour that challenged them"   **Sandy/ 390** "staff are very hesitant that that should be shifted until we're clear we've come out of the woods"   **Sandy/ 425** "they felt very vulnerable, they felt they needed a lot of help"   **Rachel/ 237** "I think they were panicked, I think there was a lot of high emotion, generally around"   **Jay/ 69** "it's very easy to comply with these sorts of terms, because if you go into it the kind of fear that you have going into a situation which is very unpredictable and dangerous, means that your just probably very, you're very open to other people telling what to do and telling you how to think"   **Jay/ 192** "there's a one off incident that people kind of um, that sticks in their mind and that can be very scary so there needs to be a bit of a booster in terms of being contained"   **Jay/ 349** "kind of contain all of their fears and worries"   **Jay/ 571** "it's scary and their advice is do not take him back into the community, he is to be in hospital"

Referrers

9. Long term, cyclical nature of CB

Charlie/ 131 "it's just you know a passing thing, you know, it's not to be taken too seriously, it will just go again and then you can see again, that several times after that the behaviour keeps happening and ten years later you've got the same"

Charlie/ 333 "I was aware that this was an ongoing issue that it has been bounced backwards and forwards endless times"

Tony/ 301 "Yea a recent referral I do, is not, is still about routine"

Tony/ 549 "maybe it's the disability,"

Tony/ 550 "that's the way he has been, they have been all their life"

Tony/ 553 "some people you can get them from A to B and some people A to Z and some people it's like to B and by the time you go there you go back to there [gestures moving backwards]."

Alex/ 249 "she might grab and so but then she gets out of that phase then she goes back to normal but this was different it stayed for a bit of time"

Sam/ 166 "I could be working with them, they're in a very bad mood with me, kicking, scratching etc. Next time I see them, it's like nothing happened you know"

Sam/ 181 "this person has a long history of challenging behaviours, some quite physical and she'd been part of our service for nearly three years and it's always been quite challenging at times"

Sam/ 183 "it's always been quite challenging at times and there have been periods where things have been going very well"

Jamie/ 113 "there is a pattern almost there perhaps through their course of their life or their support they've received"

Jamie/ 154 "It had been going on sporadically, you know it would be once a year, maybe twice a year, there was a pattern there and a history that they had done so previously"

Jamie/ 185 "there was a pattern and you know we felt there was it was perhaps because it tended to happen when it was in a registered care setting where mum had gone on holiday"

Jamie/ 265 "it was a pattern of behaviour that has established itself over a quite a length of time um and yea she has been dealing with that before during the course and history of this clients life"

Appendix N: Table of refined themes and subthemes

Referrer theme	Referrer subtheme	CP theme	CP subtheme
CB as a real observed thing	• Dominant definitions of CB • CB as long term, pervasive and cyclical • Other difficulties interpreted as CB • Risk and CB inter-related	CB as a real observed thing	• Dominant definitions of CB • CB as long term, pervasive and cyclical • Other difficulties interpreted as CB • Impact of policy or guidance on understanding • Risk and CB are inter-related
CB as social construction	• CB being a challenge to others • Normalising of CB • CB is not an actual thing • Stigma associated with construct of CB • CB is a communication/ relational issue	CB as social construction	• Social construction of CB • CB being a challenge to others • People become behaviours • CB is a communication/ relational issue • Keeping an open minded, non-reductionist stance
Understanding within the system/ network	• Different views of the problem in the system • Disagreements with psychological input • Good collaborative working across the network • Consistency is key	Understanding within the system/ network	• Different views of the problem in the system • Importance of good relationships in network • Consistency is key • Impact of environment
Emotional impact of CB work	• Different emotions felt by staff in relation to CB • Importance of emotional or reflective	Emotional impact of CB work	• Emotions felt in the network • Emotions felt by CLDT • Big emotional impact working in the field –

	support for staff • Impact of staff emotions on the relationship with client		importance of reflection
Impact of power in networks	• Support workers having less power • CLDT as holders of power in system	Impact of power in networks	• CLDT holding some power • Referrers having less power • Clients hold least amount of power
Interventions	• Reactive vs proactive strategies • Beliefs relating to help seeking • Attempts to include the individual • Goals of the network • Priorities considered	Interventions	• Reactive vs proactive strategies • Too much pressure-lack of time/resource • Graded approach to intervention • Working at the individual level • Outcomes are mixed • Psychology is a precious resource

Appendix O: Final themes and subthemes for all participants

Overarching themes	Subthemes
CORE THEMES	
One: CB is a real observed 'thing'	• Dominant definitions of CB • Long term, cyclical nature of CB
Two: CB is not a real 'thing'	• CB as a social construction • CB as a challenge to others • Is it CB or is it something else • CB is communication/relational issue
Three: Understanding within the systems/network	• Different views of the problem • Consistency is key • Importance of good relationships
SECONDARY THEMES	
Four: Emotional impact of CB	• Emotions felt in the network • Importance of reflection
Five: Impact of power in networks	• Referrers have less power • CLDT as holders of power • Clients have least power