Title: Do specific adaptations need to be made to IAPT interventions to make them more accessible to patients with a learning disability?

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Submission date: 12th December 2023

Thesis portfolio word count: **36,973** (including reference lists; excluding abstracts, tables, figures & appendices)

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Acknowledgments

Firstly, I would like to thank my primary supervisor, Dr Dave Dagnan, who took considerable time out of an already busy schedule to offer his support, guidance, expertise and patience. I feel genuinely humbled by the time he devoted to supporting me, and he will forever have my gratitude. I would also like to thank my supervisor Dr Jinnie Ooi for her statistical expertise and academic competence. Her contributions have been crucial to the successful completion of this work. I must also extend my eternal gratitude to my mother, Anne-Marie Whittaker and my father, Joseph Whittaker (07.12.1951 – 28.02.2023). Both my parents have helped me in ways which I am not able to adequately articulate or express and their unquestioning support of me constitutes a debt I am not equipped to repay. Any merit that this thesis possesses is attributable to them, and my supervisory team. Its shortcomings are entirely my own. Lastly, I wish to thank my wonderful fiancé, Sophie Fannan, and our soon-to-be-born baby. Striving to make you both proud has provided me with the sense of purpose to continue moving forward when confronted with the obstacles and setbacks that doctoral study invariably entails.

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Thesis Portfolio Abstract

Background: There is a growing interest in how people with intellectual disabilities (ID) experience psychotherapy, and the extent to which mainstream psychotherapies may need to be adapted for people with ID. However, it is currently unclear whether models of the therapeutic alliance, largely developed based on the experiences of clinicians and mainstream populations, effectively describe the experiences of people with ID. The empirical basis upon which to base decisions regarding therapeutic adaptation for people with ID likewise remains nascent.

Methods: A qualitative meta-synthesis using a best-fit framework analysis examined how the therapeutic alliance is experienced by people with ID. The review specifically examined whether Bordin's model (1979) of the therapeutic alliance accurately fits the experiences of people with ID. An empirical study was also conducted to examine which factors predict recovery for people with ID accessing NHS Talking Therapies (NHSTT), (previously Improving Access to Psychological Therapies – IAPT) and whether these factors are similar or dissimilar to those which predict recovery for people from the mainstream population.

Results: Twenty studies met the inclusion criteria for the qualitative meta-synthesis. All studies were conducted in the United Kingdom (UK). The analysis found broad areas of agreement between Bordin's model (1979) and how people with ID experience the therapeutic alliance, though people with ID assigned more importance to interpersonal aspects of therapeutic processes. In the empirical study, data from 250 participants were included across two matched groups of ID (n = 125) and non-ID (n=125) participants who had accessed NHSTT services since 2013. Results suggest that the total number of sessions and disagreement on discharge were associated with recovery outcomes for both groups.

Results also suggest that baseline GAD-7 score, social deprivation, referral duration and wait to second treatment were additionally associated with outcomes for people with ID.

Conclusions: The systematic review suggests that people with ID assign greater importance to the interpersonal aspects of psychotherapy. The primary importance of interpersonal factors is not necessarily reflected in Bordin's model (1979). Further research is also needed to determine whether Bordin's model, which is predicated upon the concept of individual responsibility, can be applied as a "best fit" to people whose lives are more likely to be characterised by impaired abilities to make autonomous decisions, reduced quantity and quality of interpersonal connections, and reduced opportunities across personal, social and professional domains. The empirical study found that the factors which predict recovery for people from the general population accessing IAPT also predict recovery for people with ID. However, there appear to be factors which additionally predict recovery for people with ID. Further research is required to determine whether these findings can be replicated across a larger sample. Chapter One

Introduction

Word count: 4419

Chapter One

Introduction

The purpose of this preliminary chapter is to introduce the substantive aims of this thesis and an overarching clinical issue central to the mental health provision for people with intellectual disabilities (ID); namely, to what extent do mainstream psychotherapies need to be adapted for people with ID? The construct of ID is also introduced, with consideration given to its epistemological basis within clinical psychology. The importance of the therapeutic relationship to psychotherapy is also introduced and elucidated using examples from both history and evolutionary psychology to help place the therapeutic alliance in a broader context of interpersonal connectedness which, it will be argued, appears to be prerequisite for psychological wellbeing. In chapter two, a systematic review of qualitative literature is undertaken, which explores how the therapeutic alliance is experienced by people with ID. The review assesses the extent to which Bordin's model (1979) of the therapeutic alliance, widely recognised as a comprehensive framework and reliably applied across a variety of therapeutic modalities (Ardito & Rabellino, 2011), accurately describes the experiences of people with ID. Primarily, this review explores whether Bordin's model needs to be adapted or extended to describe how people with ID experience the therapeutic alliance. Chapter three summarises the findings of the systematic review and introduces a rationale for the empirical study, which follows in chapter four. The empirical study examines the factors which predict recovery for people with ID accessing Improving Access to Psychological Therapies (IAPT) services, and examines whether these are similar or dissimilar to those factors which predict recovery for clients from the mainstream population. The findings of this study will contribute to the current understanding of whether mainstream psychotherapies require adaptation for people with ID. Chapter five summarises the findings of both the systematic review and empirical study and examines their contribution to the

central question of therapeutic adaptation. The strengths and limitations of the current thesis will be considered, while the implications for future research will also be outlined.

Intellectual disability: concepts and context

The primary clinical issues investigated in this thesis are facets of a deeper question which is both psychological and philosophical in nature; to what extent are the underlying processes that affect mental health in the general population similar or dissimilar to those with ID? Evidently, the answers to this question may have important implications for clinical practice. "Intellectual disability" describes impairments in cognition across a range of domains, including learning and memory, and executive functions such as planning and prioritizing. Impairments in these domains are associated with impairments in social and practical skills, such as language, social and self-care skills, although impairments across cognitive and social domains are, of course, not unique to people with ID (Dagnan, Taylor & Burke, 2023). People with ID are also a heterogeneous population and display a wide range of abilities, with significant differences in abilities between those with more profound disabilities compared to those with milder disabilities. Thus, making population-level generalisations with respect to therapeutic adaptations, or extrapolating generalizations based upon population-level data to individuals within that population, is difficult.

People are usually designated as having an intellectual disability if the following three characteristics are met.

- A significantly reduced ability to understand new or complex information and to learn new skills, usually measured with an intelligence scale and interpreted as a person having an intelligence quotient (IQ) score below 70, with:
- A reduced ability to cope independently, usually measured using a structured assessment of adaptive behaviour including home, community and social skills;

• Which started before adulthood, with a lasting effect on development (Department of Health, 2001).

Impaired intellectual functioning undoubtedly impacts across a breadth of human activity and people with ID are more vulnerable than mainstream clients in various ways. For example, they are likely to be particularly dependent upon supportive relationships to navigate the complexity of the institutional and interpersonal world. There is some evidence to suggest that the incidence of mental health difficulties is higher amongst people with ID relative to the general population (Cooper et al., 2007). The reasons for the putative higher rates of mental ill-health are varied and complex, ranging from biological to psychosocial. Paradoxically, research suggests that uptake of mental health services by people with an ID (Dekker & Koot, 2003; Einfeld et al., 2006) falls significantly short of the prevalence of mental ill-health in this population (Einfeld, Ellis, & Emerson, 2011; Einfeld & Tonge, 1996; McCarthy & Boyd, 2002; Morgan, Leonard, Bourke, & Jablensky, 2008). This may be partly attributable to the variety of barriers faced by people with ID when trying to access healthcare, including organisational barriers and those relating to service availability and quality (Whittle et al., 2018). Thus, the cognitive deficits associated with ID thus present a particular set of contingencies which are worthy of particular consideration during psychotherapy.

However, while it is necessary to acknowledge the social vulnerabilities and intellectual impairments associated with ID, there has also been a history of regarding people with ID as categorically distinct from mainstream populations, in a manner which has arguably impeded a deeper understanding of their needs. It is worth recalling that, as recently as 1983, a meta-analysis sincerely questioned whether depression and anxiety were categories of experience available to people with ID (Sovner & Hurley, 1983). Unsurprisingly, people with ID were found to manifest the full range of affective disorders. A recent meta-analysis by Tapp and colleagues (2023) also suggests that people with ID benefit from mainstream psychotherapeutic modalities such as CBT, though one should be mindful of the nascent nature of this field of research. Nonetheless, there is a developing interest in the extent to which mainstream therapeutic modalities require adaptation to be made accessible to people with ID (Weston, Hodgekins & Langdon, 2016; Surley & Dagnan, 2017). This contrasts with views widely held about people ID, at least until relatively recently. Namely, they would experience cognitive and behavioural based therapies as wholly inaccessible due to their intellectual impairments. As such, psychological therapies were rarely used to treat people with ID and a diagnosis of ID was often part of the exclusionary criterion for mainstream psychotherapy (Hollins & Sinason, 2017).

Other client groups, such as those with autism, have also been regarded as distinct from typically developing populations in quite profound ways. For example, despite a strong body of evidence attesting to primacy of the therapeutic alliance in psychotherapy for typically developing populations, some researchers have suggested that it may not be useful to make an empathic therapeutic relationship the basis of clinical work when working towards treatment goals and adaptive psychological change with autistic patients (Hare & Flood, 2001; Anderson & Morris, 2006). While exploring such issues is entirely valid, it would also be quite remarkable if interpersonal factors within therapy were unimportant to people with ID, or if attempts to develop a therapeutic relationship were observed to be counter-productive, given the centrality of the therapeutic relationship to psychotherapy, and the importance of interpersonal relationships for humans as a species (Ardito & Rabellino, 2011; Holt-Lunstad et al., 2015). Thus, while thinking in categories may have some utility when trying to organise complex information, thinking in categories can also obscure differences and heterogeneity within groups, while simultaneously obscuring important similarities and congruence between groups (Sapolsky, 1994).

This chapter will present an initial rationale as to why the therapeutic relationship is routinely associated with positive clinical outcomes. This rationale expands upon Baumeister and Leary's (1995) contention that the desire for interpersonal attachment may well be one of the most far-reaching and integrative constructs currently available to understand human nature. This argument suggests that humans are not only motivated by a fundamental desire to forge and maintain meaningful attachments, but that such attachments represent a basic human need. There seems little reason to suppose that this argument is somehow less applicable to those with ID than to those without.

Epistemological considerations

Prior to the elaboration of this initial rationale, the epistemological basis of the current thesis, namely critical realism or rationalism, must be defended. Firstly, a comprehensive rationalism is untenable. As Popper (2002) reasoned, neither logical argument nor experience can establish the rationalist attitude. Only those who are ready to consider the arguments of others and their own experience, and who have therefore already adopted a rationalist attitude, will find evidence and argument persuasive. Thus, rationalism presupposes the principle of reason and takes for granted that a reasoned approach to evidence is self-evident. As the numerous ideologies which have captured human societies throughout history attest, one cannot presuppose that evidence and argument will be interpreted in an intellectually honest fashion. Indeed, no evidence or argument could persuade someone of a particular proposition who has decided, a priori, that they do not value evidence and rationality. Measurement and analysis thus require a pre-analytic cognitive act (Sowell, 2012), in this instance a faith in reason and an assumption that a commitment to clear and honest communication represents a foundational procedural – and moral – principle that warrants no further explanation (Popper, 2002; Sowell, 2012). Secondly, framing novel results within an *a priori* theoretical framework is an inherent aspect of research as one cannot make any

observation without a certain set of presuppositions. Observation is inherently selective and presupposes a theoretical perspective (Popper, 2002). As Sowell (2012) elaborates, if one is to identify and report relevant and salient information – selected out of the potentially infinite amount of information in the surrounding environment – this presupposes a theoretical perspective or vision of causal connections. A prior vision has inevitably shaped the present analyses, and it is important to acknowledge this vision, to both be transparent and avoid the unconscious application of a particular point of view. Critical rationalism thus shares with social constructivism the view that theories are ultimately human-made constructions, rather than inherent aspects of an external reality. However, critical realism contrasts starkly with relativistic perspectives, which appear to be an unconstrained species of social constructivism, suggesting not only that an infinite number of perspectives can be made of any data, but that any attempt to construct a hierarchy of interpretations, based on criteria such as validity and reasonableness, is merely a reflection of socio-political dynamics or is merely an expression of power dynamics between individuals or institutions. This is not to diminish the significance of power dynamics, which are justifiably an important issue within ID research and clinical practice. However, this thesis takes it as axiomatic that complex phenomena cannot be explained with reference to univariate causes.

The therapeutic bond in psychotherapy

The therapeutic alliance has long been recognised as central to psychotherapy. Several meta-analyses have revealed a relationship between therapeutic alliance and clinical outcomes across various types of therapeutic modalities and clinical populations, providing robust evidence that the therapeutic alliance is an important contributing factor to clinical outcomes across a broad spectrum of client demographics, treatment modalities, clinical presentation and methodologies (Flückiger et al., 2012; Hatcher, 2010; Norcross, 2011; Stiles, 2009; Wampold, 2001). Conceptualizations of the alliance have shifted markedly in

the past century. Freud classically believed that the primary goal of psychotherapy was the analysis of transference. He thus advocated an approach to the client-therapist relationship characterised by opacity, based on his belief that "the less the therapist's real self appears, the more readily does the client transfer onto him feelings that belong elsewhere (Yalom, 1980, 412)." According to Freud, the primary discipline of psychotherapy was the objective interpretation of transference, rather than a person-centred encounter with the client. Therapists should thus aim to facilitate transference by adopting the position of a disinterested scientific observer. According to this view, if therapists failed to retain an emotional distance from their clients, they would sacrifice the objectivity necessary to effectively analyse their client. A wholly different approach to the client-therapist relationship was advocated by Rogers (2003) and Yalom (1980) who, in developing their respective client-centred and existential perspectives, suggested, not only that the effectiveness of psychotherapy was predicated upon a genuine relationship between client and therapist, but that a genuine relationship could have healing and restorative qualities in and of itself. Naturally, there remains ongoing debate as to precisely what the underlying mechanisms of psychotherapy are. Beck (Beck et al., 1979), for example, conceptualised the therapeutic bond in more pragmatic and instrumental terms than Yalom and Rogers, placing greater emphasis on the cognitive-behavioural techniques in generating positive psychological change. An interpersonal bond is important from Beck's perspective in that it supports the client to remain motivated to engage during periods of therapy when then specific techniques are not yet generating positive change (Beck, 1979). Thus, in CBT, formulation and alliance are important initial steps as part of a change process, whereby one develops both behavioural and cognitive skills during the therapeutic intervention which drive psychological change.

However, while not seeking to directly contradict the "Beckian" perspective or Freudian perspectives on the alliance, the present thesis will draw attention to a substantial body of research which suggests that being connected with genuine relationships represent a basic need for humans. Thus, Rogers' and Yalom's core idea that a therapeutic relationship, characterised by qualities such as genuineness and authenticity, can have healing and restorative qualities may be grounded in a broader truth about the basic needs of human beings as such.

Interpersonal connectedness and evolutionary psychology

Baumeister and Tice (1990) suggest that humans have various innate fears including snakes, rotting flesh, the dark, falling from heights, biological contamination (i.e. pathogen avoidance; Curtis, de Barra & Aunger., 2011) and rapidly approaching objects (Ren & Tao, 2020). Baumeister and Tice (1990) also propose a compelling hypothesis that humans possess an innate need to belong to social groups. As Gilbert (2010) reasons, threats of social exclusion and ostracism may thus activate deep-seated archetypal fears and preoccupations linked to rejection, abandonment, isolation, shame, and harm. Although many ancestral threats now pose minimal risk to humans in modern society, the prospect of social exclusion is a risk to which humans remain pervasively exposed. As will be discussed, the spectre and reality of social exclusion are particularly pertinent issues for people with ID.

Few can reasonably doubt that the loss of social attachment, the dissolution of social bonds and estrangement from meaningful, interpersonal connections are sources of profound psychological distress (Baumeister & Leary, 1995). Baumeister and Tice (1990) hypothesise that anxiety, deriving from a basic human need to belong to groups, is a species-typical adaptation to objective or potential social exclusion. From an evolutionary perspective, survival in adverse conditions is best facilitated within supportive social structures by offering cooperation with difficult tasks, distribution of finite, survival-related resources,

reciprocal alliances, and protection against danger. The necessity of group membership for survival may explain why anxiety is so often focussed on matters relating to social status and desirability (Baumeister & Tice, 1990). This seems consistent with Yalom's observation that, amongst "neurotic" individuals (Yalom's term), "the sense of personal security is so tentative that they extend their defensive parameters a long way into space". "Neurotic" people can become "inordinately stressed at threats to their career or any number of other attributes" including their sense of personal prestige, sexual prowess, physical capabilities (Yalom, 1980, p.163). Strikingly, all these examples relate in some sense to social status, competence or desirability. For example, employment is one of the ways in which humans bring forward their distinctive contribution to communal life. If this contribution is felt to be counterproductive, or is systematically undermined or invalidated by others, it results in psychological distress, perhaps because it signals that a person's membership within a social group is relatively less secure. This also suggests that the experience of anxiety is not confined to the specific moment of social exclusion. Instead, humans learn to anticipate forms of behaviour which may result in social exclusion or identify individuals within their social group who have sufficient influence or dominance to exclude others (Baumeister & Tice, 1990). Anxiety thus can be felt in response to any event or interaction that contains an implied or explicit threat of social exclusion. Because of the importance of being included in a social group, individuals may internalise the need to be defined and recognized in a socially acceptable fashion (Baumeister & Tice, 1990). This may explain why forms of bullying such as reputation destruction are potent sources of negative affect and psychological distress.

Loss of social attachment in context

There are numerous examples which illustrate how the loss of social attachment, the dissolution of social bonds and estrangement from meaningful, interpersonal connections appear to be basic sources of profound psychological distress (Baumeister & Leary, 1995).

For example, in various ancient cultures, such as Ancient Greece, exile was regarded as a punishment worse than death (Foley, 2012). In Roman law, *exsilium* was denoted as a capital punishment alternative to the death penalty. Prisoners, meanwhile, experience profound affective distress when deprived of social contact, which provides a rationale as to why solitary confinement is considered a severe form of punishment even in prison, when one has already been deprived of basic rights such as liberty, freedom of association and privacy (Strong et al., 2020). In more recent history, Alexis de Tocqueville (1876, p. 339) commented on the psychological distress experienced by those who experience thoroughgoing and pervasive forms social ostracism in democratic society, describing this in terms that would be recognised by the ancient Greeks, namely as a fate "worse than death".¹

Another instructive historical reference point when considering the distress associated with social isolation is Christopher Browning's *Ordinary Men* (1998) a focused examination of Reserve Police Battalion 101 of the German Order Police, which perpetrated the mass killing of unarmed non-combatants, including children while rounding up Jewish people in Poland for deportation to Nazi concentration and extermination camps in 1942. Such acts represent the most profound ethical breaches recognised under international law. When exploring the psychological factors which contributed to the commission of such crimes, Browning noted that the affective and psychosomatic states experienced by the perpetrators strongly suggest they were not explicitly prepared for the task of killing people in such close proximity. One of Browning's key insights is that though individuals within the group who

¹ "Tyranny in democratic republics does not proceed in the same way, however. It ignores the body and goes straight for the soul. The master no longer says: You will think as I do or die. He says: You are free not to think as I do. You may keep your life, your property, and everything else. But from this day forth you shall be as a stranger among us. You will retain your civic privileges, but they will be of no use to you. For if you seek the votes of your fellow citizens, they will withhold them, and if you seek only their esteem, they will feign to refuse even that. You will remain among men, but you will forfeit your rights to humanity. When you approach your fellow creatures, they will shun you as one who is impure. And even those who believe in your innocence will abandon you, lest they, too, be shunned in turn. Go in peace, I will not take your life, but the life I leave you with is worse than death."

a collective *did* receive such orders. As Browning (2001, p. 185) reasons, to have refrained from participating would have constituted "refusing one's share of an unpleasant collective obligation". In other words, it would represent an asocial act, contrary to the norms of the group, with concomitant risks of isolation, rejection, ostracism and alienation. Thus, participating in mass executions and "perpetrating, failing to prevent, and bearing witness, to acts that transgress deeply held moral beliefs and expectations" (Litz et al., 2009, p.700) was less aversive and terrifying than the prospect of social ostracism, particularly in a wartime environment surrounded by a hostile population (Browning, 2001). Thus, the threat of social ostracism – Browning notes there are no records of soldiers facing formal punitive responses for refusing to participate in the massacre of civilians – appears to have played a central role in incentivising participation in forms of behaviour which violated basic, inherent notions of morality that would otherwise have been unconscionable. Hence Browning's concluding observation: "to adopt overtly non-conformist behaviour was simply beyond most men. It was easier for them to shoot" (Browning, 1998, p.184).

These apparently discrepant examples attest to a relationship between objective or threatened social ostracism and profound psychological distress. However, to regard the desire for meaningful attachment as an intrinsic need, it must be demonstrated that its absence results in more than the profound negative affect. In delineating a criteria of testability, Baumiester and Leary (1995, p.498) suggest that a fundamental motivation should produce effects readily observable under all but aversive conditions. However, what is remarkable about the need for belongingness is that this need seems particularly evident in circumstances characterised by severe material privation and mortal risk. Fritz (1996), for example, observed that social bonds and social resilience are often reinforced by natural disasters, resulting in pervasive psychological health in survivors of natural disasters, contradicting the intuitive assumption that societal disasters would inevitably result in

widespread psychiatric distress and social dislocation. Fritz comments: "The distinction between "disaster" and "normal" conditions is implicit in most treatments of disaster behaviour. The everyday, ongoing life of the society is usually equated with the "normal," and those conditions that result from disaster are viewed as "abnormal" and pathological. However, in our haste to draw this distinction, we often conveniently overlook the many sources of stress, strain, conflict, and dissatisfaction that are imbedded in the nature of everyday life" (Fritz, 1996 p.22). Similarly, Lyons, (1973) observed, following a study of the psychological effects of violence in Belfast, that levels of depressions and suicidality were higher in cities without pervasive violence. The study notes: "When people are actively engaged in a cause their lives have more purpose... with a resulting improvement in mental health." Lyons (1973, p. 390) concludes by saying: "it would be irresponsible to suggest violence as a means of improving mental health, but the Belfast findings suggest that people will feel better psychologically if they have more involvement with their community." Perhaps the most compelling evidence for interpersonal connectedness being an intrinsic human need emerged from a meta-analysis from Holt-Lundstad and colleagues (2015) which examined 70 independent prospective studies, with a combined 3,407,134 participants, followed for an average of 7 years. The analysis revealed a significant effect of social isolation, loneliness, and living alone with respect to mortality risk. The increased likelihood of mortality was 26% for loneliness, 29% for social isolation and 32% for living alone. Holt-Lundstad and colleagues (2015) conclude that deficits in the quantity and quality of interpersonal connectedness is a primary predictor of premature death, comparable with, and sometimes exceeding, other well-known risk factors such as obesity, alcohol consumption and smoking.

Thus, the loss of social attachment, the dissolution of social bonds and estrangement from meaningful, interpersonal connections appear to be primal sources of psychological

distress and cumulative, long-term physiological harm, resulting in an increased all-cause mortality risk. This finding supports Baumeister and Leary's (1995) proposition that belongingness can be considered almost as compelling a need as the need for food. Indeed, the findings of Holt Lundstad and colleagues (2015), in particular, present an interesting challenge to Maslow's hierarchy of needs, which states that physiological and safety needs are more basic than needs relating to love and belongingness. A lack of belongingness appears to constitute a severe form of privation and appears to be associated with a cascade of psychological ill-effects (Baumeister and Leary, 1995) and deleterious physiological effects resulting in chronic illness and early mortality (Holt-Lunstad et al., 2015). It therefore seems reasonable to grant some credence to Baumeister and Leary's (1995) central contention that the desire for interpersonal attachment may be one of the most far-reaching and integrative constructs currently available to understand human nature. If this perspective has any merit, there seem few good reasons to suppose that the underlying processes that cause humans to depend upon strong interpersonal relationships are somehow different for people with ID. Indeed, it seems more consistent with the principle of parsimony to assume that all humans partake of the same basic essence.

The belongingness hypothesis may in fact be particularly important for people with ID, and that it is likely to be important for psychotherapy, the therapeutic alliance and therapeutic outcomes for people with ID. It is now well-established that the presence of social and interpersonal relationships has a well-established moderating effect on negative life events (Brown & Harris, 1978). However, people with ID often live isolated lives and feel excluded from their local communities (Power & Bartlett, 2018; Hall & Bates, 2019). People with ID are likelier than their non-disabled counterparts to experience a lack of supportive relationships and experience a higher level of interpersonal disruption. This vulnerability appears due to three inter-related factors; social attitudes and expectations; opportunities and

experiences; and deficits intrinsically associated with ID (Gilmore & Cuskelly, 2014). ID also remains a stigmatizing characteristic (Scior, Potts & Furnham, 2013). For stigmatized groups, the experience of prejudice and discrimination is often pervasive, ranging from acts of overt hostility and rejection to subtle insults and slights (Daley & Rappolt-Schlichtmann, 2018). Citing previous research (Link & Phelan, 2001) Daley and Rappolt-Schlichtmann (2018) explained how stigmatization occurs when perceived differences between an individual or group and other members of society lead to labelling, stereotyping, separation, loss of status, and discrimination (Link & Phelan, 2001), emphasising that people with ID are vulnerable to each of these five elements of stigma. The contexts in which individuals with ID live, learn, and work also continue to be characterised by reduced opportunities for social engagement and overt social rejection (Gilmore & Cuskelly, 2014). Difficulties with establishing and maintaining friendships may be impacted by their devalued status as well as difficulties in behaving in ways which are in accordance with peer expectations and social norms (Guralnick, 2006). The social networks of those with ID may also be restricted to others with intellectual disabilities, precluding important modelling opportunities (Gilmore & Cuskelly, 2014).

Given how many people with ID experience the interpersonal world, the therapeutic relationship may represent a particularly important, and novel, opportunity for people with ID to experience a genuine and meaningful interpersonal connection, and a relationship which is absent of the overt or implicit threats of stigmatisation and bullying (Maguire et al., 2019), threats which, for many people with ID, have indelibly marked how they experience the interpersonal world.

Chapter two

Systematic Review

Exploring how people with intellectual disabilities experience the therapeutic alliance: is

Bordin's model (1979) suitable as a "best fit" framework?

Prepared for submission to 'Clinical Psychology and Psychotherapy'²

Word Count: 11048 (excluding abstract, appendices and references)

 $^{^2}$ See Appendices E & F for author guidelines. For ease of reading, figures and tables are provided within the main body of text

Exploring how people with intellectual disabilities experience the therapeutic alliance: is

Bordin's model (1979) suitable as a "best fit" framework?

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Abstract word count: 250

Text body word count: 12424

Tables: 2

Figures: 1

Abstract

Purpose: There is an increasing interest in the use and effectiveness of mainstream psychotherapies for people with intellectual disabilities (ID) and in therapeutic processes within psychotherapy for this client group. Bordin's (1979) model is a comprehensive framework of the alliance which has been applied across a variety of therapeutic modalities and clinical populations. However, little research has considered its applicability for people with ID.

Method: A comprehensive search of the qualitative literature on how people with ID experience psychotherapy was undertaken, identifying twenty papers that met eligibility criteria. Studies were included if they contained qualitative data relating to how people with ID experience psychotherapy and examined qualitative data relating to the therapeutic alliance. A "best fit" framework synthesis methodology (Carroll et al., 2013, 2011) was used to explore the applicability of Bordin's model to the experiences of the therapeutic alliance described by people with ID.

Results: the analysis supported the superordinate themes (bond, task and goals). It was notable that people with ID seem to emphasise the experience of the bond and did not substantially differentiate task and goals. The degree to which the therapist acted in the life of the client was represented in an additional theme of 'context'.

Conclusion: Results suggest that the core elements of Bordin's model are described by people with ID. However, people with ID described a broader experience of the bond and this is seen in the number of sub themes identified. Suggestions for further research and clinical implications are discussed.

Keywords: Therapeutic alliance; Bordin; intellectual disability; qualitative; bond; tasks; goals

Introduction

There has been an increased focus on the use and effectiveness of mainstream psychotherapies for people with ID (Dagnan, Taylor & Burke, 2023) and in therapeutic processes within psychotherapy for people with ID (Jahoda, Dagnan, Stenfert Kroese, Pert, & Trower, 2009; Dagnan, Pulford, Cathers, & Jahoda, 2016). In considering therapy processes, a range of common factors have been identified in the literature. For example, Cuijpers et al (2019) review common factors such as therapist expertise, therapist warmth, and therapy structure and consider the relationship between these factors and psychotherapeutic outcomes. There is also broad agreement on the importance of the therapeutic alliance as a key element of common process within psychotherapy. Several meta-analyses suggest a robust relationship between therapeutic alliance and positive clinical outcomes across a range of client demographics, treatment modalities and clinical presentations (Ardito & Rabellino, 2011; Hovarth & Symonds, 1991). Though the key qualities of the therapeutic alliance continue to attract analysis and commentary (Flückiger et al., 2012; Stubbe, 2018), Bordin's (1979) model is widely recognised as a comprehensive framework which can be applied reliably across a variety of therapeutic modalities (Ardito & Rabellino, 2011) and group psychotherapy (Pinsof, 1988; Pinsof & Catherall, 1986). Indeed, Bordin's model was designed to be 'pan-theoretical' as it was developed in a context characterised by a proliferation of psychotherapeutic approaches. Bordin's model was designed to be counterweight to what he perceived as a trend towards solipsism, whereby each therapist may eventually employ their own idiosyncratic techniques (Bordin, 1979). He thus sought to elaborate the working alliance in comprehensive and universally applicable terms to ensure that the plurality of therapeutic approaches cohered around some central axioms. Though empirical research supports the application of Bordin's model across a range of clinical contexts, little research has considered its applicability for people with ID. One small-scale

study (Cameron, Swanton & Dagnan, 2020) examined the use of Bordin's model in talking therapies for people with intellectual disabilities, concluding that the way participants with ID experienced the therapeutic alliance was potentially well described by Bordin's framework. However, given the dearth of literature, it is important to further test the applicability of Bordin's model for this client group.

Bordin's model: context and concepts

Bordin (1979) conceptualised the therapeutic alliance as consisting of a strong, reciprocal bond between client and therapist, a shared understanding of treatment goals and agreement on the nature of tasks to be undertaken during therapy. Bordin also suggested that the alliance will be stronger if goals and tasks are collaboratively agreed. One of the strengths of this model is that it recognises the interrelatedness of therapeutic techniques and bond, thus challenging the view that interpersonal factors and therapeutic techniques are separate elements of therapy. Though some have suggested this strength represents a novel conception of the alliance (Ardito & Rabellino, 2011), the interrelatedness of bond and therapeutic content has been acknowledged by others, particularly Yalom (1980) and Rogers (1961; 1964), who both recognised the importance of a strong therapeutic relationship alongside the therapist's technical competencies and professional experience.

Central to Bordin's model of the alliance is trust (Bordin, 1979, p.254). Interpersonal trust is not a single overarching factor within Bordin's model, but rather one which is present (or not) across the whole alliance model. Trust is an assumption – often in the absence of complete information – that a potential interaction partner will proceed in good faith and with integrity. Trust has previously been conceptualised as a fundamental natural resource in that it facilitates mutually beneficial, long-term cooperation between people (Arrow, 1972). This insight is helpful when conceptualising its centrality to Bordin's model. As Ardito and Rabellino (2011) explain, agreement and goals and tasks, and cooperation in the ongoing

service of goals and tasks, can only occur if there is a personal relationship grounded in confidence and mutual positive regard, since any agreement on goals and tasks requires the client to believe in the therapist's competence. In turn, the therapist must invest their belief in the client's resources, or what Rogers termed the client's *actualising tendency* (Rogers, 1961; 1964). The alliance, therefore, is a joint enterprise which functions best when grounded in mutual trust.

Bordin's model has been interpreted as suggesting that the bond influences therapeutic outcomes, not because it is healing in and of itself, but rather because it enables the client to accept, adhere to, and believe in the therapeutic techniques, specifically the vividness of the links made by the therapist between goals and tasks (Prusiński, 2022). This view suggests that the therapeutic bond represents a foundational component of therapy, while adherence to the therapeutic goals and tasks represents the active technology of therapy which drives therapeutic change. This implies that the bond is a foundational component of the Bordin's triad, identifying a clear inter-relationship between bond, goals and tasks (Ardito & Rabellino, 2011; Prusiński, 2022). However, a hierarchical structure is not immediately evident in Bordin's original description. Rather, Bordin acknowledges an interactive quality between bond, goals and tasks. For example, Bordin states that the therapeutic task of directing attention towards "the more protected recesses of inner experience" develops deeper bonds of trust and attachment. He further states that both client and therapist will be "more concerned about liking or disliking each other if they are proposing to settle into a working relationship" (Bordin, 1979, p.254.). These examples suggest an interactive and bi-directional relationship between bond, tasks and goals, rather than a formally hierarchical one.

Furthermore, though Bordin proposed "an elegantly succinct theory of the therapeutic alliance" (Ross, Polascheck & Ward., 2008, p. 465), its constituent elements are, in some sense, subdivided in complex fashion. Bordin highlighted "empathic understanding,

communicating, interpreting, self-disclosing" as paradigmatic examples of *therapeutic tasks*. It is, however, unclear whether examples of task-related activities, such as empathic understanding, can be differentiated from the interpersonal bond. The concepts of communicating and self-disclosing are equally hard to parse into discrete categories. Likewise, neither Bordin nor recent reviews have fully elaborated the core qualities of the therapeutic bond (Bordin, 1979; Ardito & Rabellino, 2011). Rogers (1964) notably, attempted to define the necessary qualities therapists must embody to develop a genuine therapeutic relationship with their participants, such as authenticity, genuineness, warmth and accurate empathy. Yalom (1980) and Kaiser (2012) also emphasised that the therapist's disposition of receptiveness is central to psychotherapy. However, key aspects of the bond were not formalised within Bordin's model and, as such, it remains a somewhat abstract, complex and non-specific construct.

Another core element of Bordin's model is the willingness of the client to assume individual responsibility. This principle informs a range of psychotherapies (Rogers, 1964; Yalom, 1980), which rests on the shared acceptance that the client's suffering is, to a greater or lesser extent, a function of their own ways of thinking, feeling and acting. Though Bordin does not explicitly discuss disadvantaged groups, he does acknowledge people may endure life-circumstances which are profoundly damaging and beyond the scope of an individual's control. However, Bordin emphasises that a primary aim of psychotherapy is to raise the client's awareness of, and then modify or ameliorate, their own contributions to their suffering (Bordin, 1979, p.253). However, the central focus on individual responsibility within Bordin's model may raise questions about its applicability to ID client groups, given that a definitional characteristic of ID is a reduced ability to cope independently (Department of Health, 2001).

The individual responsibility at the heart of Bordin's model is also pertinent when considering the social context of disability has also been recognised as essential in understanding a whole range of ID-related issues (Jahoda et al., 2009), particularly when considering notions of autonomy and interdependency, which are key considerations for people with ID. People with ID are more likely to experience vulnerabilities due to a complex range of biological and social factors and intellectual and cognitive impairments. However, it is noteworthy when considering the applicability of Bordin's model to this group, that while such factors significantly contribute to an individual's distress, they seem to fall outside the scope of personal responsibility (Danforth, 2021). People with ID are likelier to experience a lack of supportive relationships. This vulnerability appears due to three inter-related factors; the social attitudes and expectations of others; opportunities and experiences; and deficits intrinsically associated with inherent intellectual impairment (Gilmore & Cuskelly, 2014). ID also remains a stigmatizing characteristic (Scior, Potts & Furnham, 2013), and the experience of prejudice and discrimination for disabled people is often pervasive, ranging from acts of overt hostility and rejection to more insidious forms of discrimination, such as subtle insults and slights (Daley & Rappolt-Schlichtmann, 2018). The contexts in which individuals with ID live, learn, and work also continue to be characterised by reduced opportunities for social engagement and overt social rejection (Gilmore & Cuskelly, 2014). It is also common for the social networks of those with ID to be restricted to others with ID, precluding important modelling opportunities (Gilmore & Cuskelly, 2014). It is therefore important to explore whether models such as Bordin's, which are predicated upon individual responsibility in some fundamental sense, are applicable to a client group who experience an absence of individual responsibility and autonomy across their lives.

Method

The review protocol was pre-registered on the International Prospective Register of Systematic Reviews (PROSPERO; protocol number: CRD42023395134) on 03.02.2023. Reporting of this review follows guidelines for systematic reviews (PRISMA-P; Moher et al., 2015) and qualitative evidence syntheses (ENTREQ; Tong et al., 2012).

Framework selection

This meta-synthesis explores the applicability of Bordin's model to qualitative experiences of psychotherapy described by participants with ID using a "best fit" framework synthesis (Carroll et al., 2013, 2011). "Best fit" framework analysis (BFFA) uses an already available framework against which data are coded and tested, as opposed to creating a novel framework as is the case in traditional approaches to qualitative meta-synthesis. Best fit framework synthesis takes a critical realist epistemological stance, an approach which was comprehensively elaborated in the introduction, (Booth et al., 2016) and combines an initial deductive framework analysis with a subsequent inductive thematic analysis for data that cannot be accommodated within the *a priori* framework.

The BFFA approach "offers a highly structured approach to organising and analysing data" which involves the preliminary identification of *a priori* themes from a pre-existing theoretical framework, against which to map novel data from different studies. This approach has been utilised within healthcare (Oliver et al., 2008; Carroll, Booth & Cooper, 2011; Carroll et al., 2013) although has not thus far been applied widely within clinical psychology (see Jagfeld et al., 2021 for one of the few examples of the use of BFFA in clinical psychology). BFFA is a potentially very useful as a secondary analytic technique in an area where data are otherwise limited, as it allows researchers to test whether previous research can be integrated into pre-existing *a priori* frameworks and thus supplement and revise existing theoretical frameworks. The data sets available for people with ID are limited in

number compared to other groups so methods that enable their reuse, to explore different questions are very useful.

Search strategy

The current study builds upon search strategies used in a qualitative meta-synthesis of the experience of people with intellectual disabilities in therapy (Evans & Randle-Phillips, 2020). The search terms used in this study are shown in Appendix A. The search was conducted using the CINAHL, PsychINFO, Web of Science and MedLINE databases from 1965 to the present day (Searches undertaken on 24.02.23). The search strategy utilised the subject headings facility in the CINAHL, PsychINFO (APA Thesaurus of Psychological Index Terms) and MedLINE (MeSH) databases, a complete list of which is also shown in Appendix A.³ The current search strategy identified four papers additional to those identified by Evans and Randle-Phillips (2020) which matched the inclusion criteria. Reference lists of relevant book chapters, review articles and eligible articles were screened to identify further studies missed by the electronic search.

Eligibility Criteria

The search identified primary research papers relating to the experiences of people with ID in individual or group-based psychological therapy. To be included in the current synthesis, studies were required to meet the following criteria:

- (i) To be published in English
- (ii) To be published in a peer-reviewed journal;
- (iii) To use a qualitative methodology;
- (iv) To involve a psychological therapy for emotional or mental health difficulties. The search strategy utilised Evans and Randall-Phillips (2020, p.236) definition of psychotherapy, namely "group or individual interventions that involve a

³ Web of Science does not utilise medical subject headings in its search engine.

psychological intervention aimed at the treatment of emotional, behavioural or mental health problems". The current review included only those studies based on talking therapies, as Bordin's model, which the current review was designed to test, was originally framed and elaborated within the context of interpersonal dialogue. Creative therapies, such as art-based therapies, were not included.

- To involve participants aged 18 years or older with a diagnosed ID in accordance with the DSM-IV criteria (American Psychiatric Association, 2000) or ICD-10 (World Health Organization, 1992).
- (vi) Studies involving mixed methods which met the above criteria were included if sufficient information was provided on the qualitative methodology used and the research findings.

Reasons for exclusions of studies are clarified in figure 1.

Study Selection / Screening Method

Figure 1 shows a summary of the search and screening method using a Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flowchart. Author MW screened (n = 686) all the retrieved titles and abstracts for eligibility. Second author DD checked 40% of articles discarded at title and abstract stage. The overarching logic of this approach was to ensure that no papers that should have been carried through to the final stage of analysis were excluded at prior stages. Therefore, reliability was only checked for excluded papers. No discrepant judgements were identified, and agreement was thus judged to be 100%. Author MW then assessed the full text of eligible studies (n = 82), with 20 papers deemed eligible. Author DD independently assessed 100% of the papers identified at full text stage with no disagreements identified. The meta-analysis by Evan & Randle-Phillips (2020) also served as a source of external validation, enhancing the credibility of the current search results. There was a high level of agreement between the papers identified by Evan & Randle-Phillips (2020) and the present synthesis, with the present searches identifying an additional four papers. Reference and citation searches of the included articles found no further papers.

Descriptive Data Extraction

Descriptive data extraction was completed by MW. Information extracted were the study location, the core aim of each study, participants characteristics (for example, sample size, age and sex), the therapeutic modality experienced by the clients, the data collection method and the qualitative methodology used to analyse the data. To ensure accuracy, all studies the studies were crossed-checked by DD. No disagreements in judgement were identified and agreement was thus deemed to be 100%. This information is recorded in below in *table 1*.

Figure 1: Flow chart



Study Characteristics

Table 1 outlines the characteristics of the included studies. Fourteen papers exclusively utilised qualitative methodologies while six papers used mixed methods, incorporating a qualitative component using semi-structured interviews; a decision was made to include the qualitative results from these papers as detailed qualitative data was reported. Sample sizes ranged from 3 to 20, including a total of 83 males and 62 females, although four studies did not disclose the sex of participants (35 participants in total whose gender was unknown). All studies included in the current synthesis were undertaken in the United Kingdom.

Six of the studies described experiences of CBT either individually or in a group setting (6, 7, 11, 12, 15, 18). One study exclusively described experience of psychodynamic therapy (10), while another study reported fifteen people engaging in psychodynamic therapy, two people

engaging in integrative counselling and three people engaging in CBT (8). Four studies described experience of dialectical behaviour therapy (DBT) (3, 14, 17), and one study described experience of compassion-focused therapy (CFT) (5). Four studies stated people received individual psychotherapy (4, 9, 13, 16) while one study did not disclose the psychotherapeutic modality (20).

Participants in one study (1) had engaged in various therapeutic modalities: psychodynamic therapy (two clients), systemic therapy (one client), cognitive analytical therapy (CAT; one client), CBT (one client) and cognitive behavioural plus acceptance and commitment therapy (ACT; one client). Seven studies involved group-based therapy, ten involved individual therapy and three implemented a comprehensive DBT schedule, involving both individual and group-based therapy.

Six studies (1, 6, 10, 11, 13, and 16) used formal IQ score to establish the level of intellectual impairment of participants, indicating that participants within these studies ranged from mild to moderate intellectual disability. Six studies (1, 3, 12, 15, 17, 18) indicated participants had mild intellectual disabilities and five studies reported participants had mild to moderate intellectual disabilities (2, 5, 6, 14, 20), though these studies did not conduct a formal IQ tests. The remaining studies (4, 7, 8, 9, 10, 11, 13, 16, and 19) did not comment on the level of intellectual disability of participants.

With respect to analytic approaches, studies predominantly used either Thematic Analysis (Braun and Clarke, 2006) (six) or Interpretative Phenomenological Analysis (IPA; Smith & Osborne, 2003) (twelve). One study used content analysis (6) while another study did not disclose its qualitative analytical approach (7). Please see Table 1 for a complete summary of the characteristics of the studies included in the current synthesis.

| Table 1: Study Characteristics | | | | | | | | |
|--------------------------------|---------------------------------------|--|--|--|---|--|--|--|
| Study number | Paper authors and year | Country within which study based | Core aim of study | Participants characteristics (Age, sex) | Therapy experienced by participants | Data collection method | Analytic approach | |
| 1 | Cameron, Swanton and Dagnan (2020) | United Kingdom (UK) | Exploring the relevance of Bordin's model for adults with intellectual disabilities | 3 females, 1 male. Aged 24–48 years. | Mixed: Psychodynamic therapy (2), systemic therapy (1), cognitive analytical therapy (CAT; one client), CBT (1) and cognitive behavioural plus acceptance and commitment therapy (ACT; 1). Mean number of therapy sessions at the time of interviews was 34 sessions. | Structured individual interviews. | Thematic analysis (Braun and Clarke, 2006). | |
| 2 | Croom et al. (2021) | UK | Exploring the experiences of adults with Intellectual Disabilities attending a mindfulness-based group intervention | 2 females, 1 male. Aged 19–56 years. | Mindfulness-based intervention programme | Open-ended group and individual interviews. | Thematic analysis (Braun and Clarke, 2006). | |
| 3 | Crossland et al. (2017) | UK | Examining the outcomes and experiences of an adapted Dialectic Behaviour Therapy skills training group for people with intellectual disabilities | 3 females, 1 male. Aged 24–48 years. | 18-week DBT skills training group. | Individual semi- structured interviews. Mixed methods | Thematic analysis (Braun and Clarke, 2006). | |
| 4 | Gifford et al. (2013) | UK | What is it like to work with a clinical psychologist of a specialist learning disabilities service? Views from people with learning disabilities | 2 females, 6 males. Aged 27–46 years. | Individual psychological therapy (Psychological input varied from 3 to 24 months). | Individual semi- structured interviews. | Thematic analysis (Braun and Clarke, 2006). | |
| 5 | Hardiman et al. (2018) | UK | The experiences of people with a learning disability in Compassion Focussed Therapy | 2 females, 1 male. Aged 31–48 years. | Compassion focussed therapy (12-15 week therapy schedule). | Individual semi- structured interviews. | Interpretative Phenomenological Analysis (IPA) (Smith & Osborne, 2003). | |
| 6 | Hassiotis et al. (2013) | UK | Exploring the experiences of clients with a learning disability with depression and/or anxiety during a manualised CBT | Information not disclosed | Individual CBT for mood disorders (Psychological input occurred over 16 weeks). | Individual semi- structured interviews. | Content analysis (Vaismoradi et al., 2013). |
|----|---------------------------|----|---|---|---|---|---|
| 7 | Hays et al. (2007) | UK | Service user views of group treatment for men with intellectual disability and sexually abusive behaviour | 16 males. Aged 20–61 years. | Group-based CBT for individuals with ID with a history of sexual offences. The group occurred over 1 year. | Individual semi- structured interviews. | Information not disclosed. |
| 8 | Khan and Beail (2013) | UK | Exploring service user satisfaction with individual psychotherapy for people with intellectual disabilities | 8 females, 12 males. Aged 17–64 years. | Mixed: Psychodynamic therapy (15), integrative counselling (2) and CBT (3). | Individual semi- structured interviews. | Thematic analysis (Braun and Clarke, 2006). |
| 9 | Lewis et al. (2015) | UK | Exploring how people with Learning Disabilities' Experience of Psychological Therapy | 5 females, 1 male. Aged 20–43 years. | Individual psychological therapy. | Individual semi- structured interviews. | IPA (Smith & Osborne, 2003). |
| 10 | Macdonald et al. (2003) | UK | Exploring how people with learning disabilities experience group analytic therapy | 5 females, 4 males, Ages of participants not disclosed. | Two groups based on psychodynamic group psychotherapy. One group for clients with a history of sexual offending. The other was a women's group. The four male participants had been attending the group for over a year. The five female participants had been in the group for 2–8 months | Individual semi- structured interviews. | IPA (Smith & Osborne, 2003). |
| 11 | MacMahon et al. (2015) | UK | A qualitative study of service users' experiences of a CBT anger management group intervention | 3 females, 8 males. Aged 22–44 years. | Group-based CBT for anger management (12 sessions). | Individual semi- structured interviews. | IPA (Smith & Osborne, 2003). |
| 12 | Marwood and Hewitt (2013) | UK | Evaluating an anxiety group for people with | Information not disclosed. | Group-based CBT for anxiety (six sessions). | Individual semi- structured interviews. | IPA (Smith & Osborne, 2003). |

| | | | learning disabilities using a mixed methodology | | | Mixed methods. | |
|----|----------------------------------|----|--|--|--|--|---|
| 13 | Merriman and Beail (2009) | UK | Service user views of long-term individual psychodynamic psychotherapy | 6 males. Aged 22–45. | Individual psychotherapy (therapeutic input occurred for two or more years). | Individual semi- structured interviews. | IPA (Smith & Osborne, 2003). |
| 14 | Pearson et al. (2021) | UK | Exploring the experiences of dialectical behaviour therapy in a community setting for individuals with intellectual disabilities, | 8 females, 3 males. Aged 26–52 years. | DBT group skills training. | Individual interviews using a flexible interview schedule, suggesting semi-structured interviews. | IPA (Smith & Osborne, 2003). |
| 15 | Pert et al (2013) | UK | Investigating process issues in CBT from the perspective of clients with mild intellectual disabilities | 7 females, 8 males. Aged 26–52 years. | Individual CBT-based psychotherapy | Two individual semi-structured interviews. | IPA (Smith & Osborne, 2003). |
| 16 | Ramsden et al. (2016) | UK | Perceived barriers and facilitators to positive therapeutic change for people with intellectual disabilities | 6 males. Aged 19–43 years. | Individual psychological therapy completed within the last 3 months. | Individual semi- structured interviews. | Thematic analysis (Braun and Clarke, 2006). |
| 17 | Roscoe et al. (2016) | UK | Exploring Service users' perspectives of dialectical behaviour therapy in an in client unit for women with a learning disability | 10 females. Aged 19–57 years. | DBT-based skills training programme. Participants had been receiving DBT for varying lengths of time (between 3–23 months). | Individual semi- structured interviews. | IPA (Smith & Osborne, 2003). |
| 18 | Stenfert Kroese et al. (2016) | UK | A pilot study of trauma- focussed cognitive- behaviour therapy for people with mild intellectual disabilities | 3 females, 2 males. Aged 21–46 years. | Group-based trauma-focused CBT. Therapeutic input occurred over 12 weeks. | Two individual semi-structured interviews. Mixed methods. | IPA (Smith & Osborne, 2003). |

| 19 | Thomson and Johnson (2017) | UK | Exploring the experiences of women with learning disabilities undergoing dialectical behaviour therapy in a secure service | Information not disclosed. | DBT skills-based programme. | Two individual semi-structured interviews. | IPA (Smith & Osborne, 2003). |
|----|---|----|---|--|---|--|---------------------------------|
| 20 | Trustam, Chapman and Shanahan (2020) | UK | Exploring the recovery experiences of people with intellectual disabilities | 3 females, 4 males, Aged 20–54 years. | Undisclosed. Participants interviewed following completion of documented mental health treatment. | Individual semi- structured interviews. | IPA (Smith & Osborne, 2003). |

Quality appraisal

Following current recommendations for qualitative evidence syntheses, quality of the included studies was assessed to review methodological rigour but not to exclude studies (Dixon-Woods et al., 2007; Thomas and Harden, 2008). Appendix 3 presents the CASP (Critical Appraisal Skills Programme, 2018) ratings for the included articles. A second rater independently appraised 50% of the articles according to the CASP criteria. The scoring tool comprises of 10 items, with each item rated as either "yes", "no" or "unclear". A higher number of "yes" ratings suggest a higher level of study quality. Assigning such ratings ultimately requires the researcher to make a judgement. The lead author of the current study (MW) rated 100% of the papers, with a second rater (DD) independently rating 50% of the papers. There were 2 disagreements across 100 ratings, indicating a 98% agreement. The discrepant ratings were then revisited and consensus on an appropriate rating was reached through discussion.

Data synthesis

The current study examined whether the conceptual understanding of the therapeutic alliance described in Bordin's model fits the experience of people with intellectual disabilities. A Best Fit Framework Analysis (BFFA) approach was therefore appropriate, based upon its application of a widely published and utilised model. As Carroll et al., (2013) explain, BFFA utilises an *a priori* framework as a scaffold around which novel findings may be brought together and organised. BFFA begins with a deductive phase where the data is fitted to the framework followed by an inductive phase where data not immediately explained by the original model is subjected to further thematic analysis and where data within a priori themes is considered with respect to potential subthemes to determine whether it expands and adds to the model. A deductive framework analysis was initially applied to the qualitative data, whereby data from the original studies was coded against the *a priori* framework of

Bordin's model, to determine the extent to which the data could be reasonably integrated and condensed into the conceptual categories of bond, goals and tasks.

Where qualitative data from the included studies could not be straightforwardly translated into Bordin's *a priori* themes, a second order inductive reflexive thematic analysis, (Braun & Clarke., 2019) was implemented. Initial line by line analysis of the results sections suggested it was unrealistic to treat each line of qualitative data as a single unit of discrete, relevant information and so analysis was typically implemented at the level of the statement in results sections. In grouping together codes and determining which codes constituted a theme, the current synthesis adopted the guidance of Braun and Clarke (2006) who suggested considering the prevalence and keyness of a theme, namely its ability to capture what is relevant with respect to the research question and applying this principle consistently across the data. Identifying emergent themes through an inductive process achieved a thoroughness and comprehensiveness to the analysis, and minimised the possibility that themes relevant to client experience were arbitrarily or unintentionally excluded. This approach allowed salient themes based on the participants' natural descriptions of their own experiences to be identified within each study (Campbell et al., 2011). The current study developed a lines-ofargument (LOA) synthesis (Noblit & Hare, 1988), developing synthetic constructs based on themes emerging directly from the qualitative data as reported in the results section of each original study. The primary aim of LOA is to "build up a picture of the whole" (Barnett-Page & Thomas, 2009, p. 2). Building up a picture of the whole is consistent with a central scientific principle identified by Feynman (1998) that researchers must try to provide all the available information to help others to judge the value and accuracy of a particular interpretation, rather than just the information that leads to judgement in a particular direction. Hence, themes which have may have had implications for the alliance but were

judged to be not directly linked with the alliance were also analysed with full theme descriptions included in appendix B.

The presence of a theme suggests particular codes have numerous occurrences across the data, although determining the presence of a theme ultimately requires the judgement of the researcher. Such judgements were based on an iterative and discursive process involving discussion between the researchers, to determine their reasonableness and robustness. Thematic comprehensiveness was inferred once synthetic constructs had stabilised, suggesting that the further coding would have been of limited utility in generating novel themes, though all available papers were coded.

Synthesis of qualitative data has been acknowledged as a highly complex, and difficult to define, process (Barnett-Page & Thomas, 2009). Ultimately, this process relied upon the judgements of the researchers, and a commitment to intellectual honesty, such that themes were not arbitrarily excluded from the analysis. Consensus was reached by discussions between the researchers to determine whether emergent themes were novel, with respect to Bordin's model, or could be reasonably integrated into the original framework.

Results

| Themes of Bordin's model | Synthetic constructs | Studies in which constructs emerged |
|-----------------------------|---|---|
| Bond | Trust | 1, 14, 15, 17, 18, 20 |
| | The therapeutic relationship as a distinctive relationship | 1, 2, 4, 5, 9, 15 |
| | Therapy is safe | |
| | Open talking [therapy characterized by talking] | 1, 2, 4, 7, 8, 9, 10, 11, 13, 14, 15, 16, 17, 20 |
| | - Confidentiality and containment | 3, 4, 5, 6, 7, 9, 10, 15, 17, 20 |
| | - No threat of negative evaluation (non- judgemental) | 1, 4, 7, 10, 12, 13, 14, 15, 20 |
| Tasks | Engaging in tasks | 3, 4, 5, 6, 7, 9, 11, 12, 14, 17, 19, 20 |
| | Lack of understanding of tasks | 2, 3, 5, 6, 8, 11, 16, 17, 18, 19 |
| | Collaboration and personal agency | 1, 9, 10, 13, 14, 15 |
| Goals | Identifiable goals | 1, 4, 9, 15, 17 |
| | Post-therapeutic change: implicit goals | 1, 4, 9, 12, 13, 14, 17, 18, 20 |
| The alliance in context | Therapists as advocate and problem solver: extending the relationship into the client's wider context | 4, 9, 13, 16 |

Table 2: summary of best fit framework synthesis

Synthesis

Table 2 summarises the best fit framework synthesis. The table identifies themes identified with the core elements of Bordin's model of alliance. The papers which contributed to the themes identified are also listed in the right-hand column of the table. The table identified three primary themes within the superordinate category of bond, one of which has three subordinate themes.

The findings can be summarised as follows: The themes which emerged broadly support the use of Bordin's model to structure how people with ID experience the therapeutic alliance. However, the elements appear not to be experienced with equal salience. Themes relating to the interpersonal bond were a particularly salient aspect of client experience and the bond was formulated as having three elements; trustworthiness, the distinctiveness of the bond and its safety. These emergent themes were judged to be consistent with the definition of the bond. Safety comprised of three components: open talking, confidentiality, and no fear of negative evaluation. Tasks were also an important aspect of client experiences though a subordinate element of 'lack of clarity on therapeutic tasks' was identified as participants often expressed a lack of clarity with respect to the content of therapy sessions. A theme of collaboration and personal agency also emerged and was incorporated into the a priori task component of Bordin's model. Goals were judged to be less well differentiated. Though some data related specifically to goals, clients often discussed therapy outcomes instead. These data nonetheless implied the existence of implicit therapeutic goals, these data were incorporated within a subtheme of implicit/emergent goals. Finally, an additional theme was identified, namely the therapist as an advocate and the therapist as a problem solver. This appears to be related to the social context of ID and this was felt to require an additional component to the alliance model. Further themes were identified and briefly discussed as precursors to alliance and as outcomes from therapy which may interact with alliance but were not judged to be not part of the core model.

BOND

Primary theme: Trust

Qualitative data relating to the therapist as trustworthy was present across several studies and is consistent with the way Bordin has previously described the bond. One client

spoke of the importance of establishing a therapeutic relationship based on trust, an emphasis which reflected the experiences of many participants:

"I just got a relationship with people who I trust and talk to, which takes for me to trust somebody quite a lot. I have been here now a long time, and [therapist] has been there since day one" (Roscoe et al., 2015, p.272).

Other participants spoke about the relationship between being genuinely listened to and placing their trust in their therapist:

"I can trust [the therapist] Interviewer: (...) So what did [the therapist] do that made you feel you could trust her? Tess: Listened. She understood" (Pearson et al., 2021, p.289).

Another aspect of trust for some participants was their faith in their therapist as competent authority, who was sufficiently skilled and who had sufficient experience to support them with their difficulties. (Pert et al., 2013). The centrality of trust seemed particularly important to participants with previous experiences of unfair treatment and a relative absence of interpersonal relationships based on trust (Trustam, Chapman & Shanahan, 2022). As one client stated:

"I can never ever trust people. That's what I say to them. You can never trust. This person could be your favourite friend, right. And you don't know what that friend's going to say to the next person. See that's why I have so many secrets, I can't tell nobody. Because I don't know who they're going to tell on to" (Macdonald, Sinason & Hollins, 2003, p.443).

Participants across various studies placed emphasis on a particular therapeutic style characterised by warmth, accurate empathy and a spirit of receptiveness to the participants' contributions, which seemed to help develop trust as therapy progressed (Pert et al., 2013). Participants across several studies specifically commented on their therapists' interpersonal skills, placing particular emphasis on qualities such as attentiveness and active listening skills, which seemed to convey a sense of genuine presence:

"When I sit there (therapist's) eyes are pointing at you. He's looking at you. He doesn't look at the wall or the (window), or you know, he's staring at you. But if he takes his eyes off you he's maybe like writing down or you know taking notes (Pert et al., 2013, p.364).

Participants seemed to experience this relational style as particularly validating, and that their difficulties were worthy of concern and consideration:

"I felt like an actual person who had the right to tell someone how he feels and not feel daft, because when I used to talk to certain ladies at my place before, when I talked to them they were just sitting there like they weren't listening, because they'd turn their faces and I'd think "okay, you're not listening"." (Stenfert Kroese et al., 2016, p.303).

For some participants, the therapist's genuine presence suggested they became a trustworthy participant and ally in their lives who had genuine concern for their wellbeing:

"The most helpful thing was she was there. She knew I had a problem, she seen it. And that was the most helpful thing" (Pert et al., 2013, p.364).

Primary theme: A distinctive relationship

Another theme which emerged across studies was that the relationship with the psychologist represented a distinctive relationship for participants. Participants frequently shared their sense that their relationship with their therapists was distinct to their relationship with other professionals, and what characterised by a "special connection" (Cameron, Swanton & Dagnan, 2020, p.172). As another client elaborated:

"It was a new person that I would seek and was different than the rest of the people that worked here" (Gifford et al, 2012, p.117).

Some participants characterised their relationship with their therapist to illustrate a sense of interpersonal connectedness:

"He's like a counsellor but he's like a friend. You could talk to him about anything and he just listens and helps you out [...] he's been like a guardian angel (Cameron, Swanton & Dagnan, 2020, p.173).

Another client commented:

"it is great to be talking to another person, like talking to a friend" (Gifford et al, 2012, p.117).

Another client contrasted the relationship with their therapist with that of family members, though again to underscore their sense of connectedness:

"It's somebody that understands how you feel. Because for all my family talk to me, but they don't talk to me in the way I want them to talk to me" (Pert et al., 2013, p.362).

For other participants, the experience of being received on an equitable basis and being treated "like an adult", contrasting with experiences of being infantilised and "treated like a child" in other contexts, also contributed to the distinctive quality of the therapeutic relationship:

"Well my (therapist) seems to think I've got the brain of an adult, she seems to think I speak like an adult and I do things in an adult way" (Pert et al., 2013, p.363).

Another client implied how he perceived his psychologist as central in his life, both as a motivating factor to remain engaged with therapy, but also as someone who helped maintain a general stability in his life:

"I don't want to let her down do I? It would be very difficult; everything would fall apart if I didn't have her" (Gifford et al, 2012, p.119).

Primary theme: Therapy is safe

There was a strong theme of therapy as a 'safe' experience, this was particularly in contrast to the world outside of therapy. This was seen in three sub-ordinate themes.

Sub-ordinate theme: Open talking

Participants spoke favourably of opportunities for open discussion both in a group setting (Marwood & Hewitt, 2012) and within one-to-one psychotherapy (MacMahon et al., 2015). As one client stated,

"I could talk about anything to her you know, didn't matter how personal it was you know", (Gifford et al, 2012, p.117).

Participants in several studies commented on the feeling that they were free to talk openly during sessions and having a sense of trust that they would be listened to, which often contrasted with experiences outside of therapy:

"...I haven't been able to talk to anybody about [my difficulties]. If I try to talk to someone, they don't want to know...If I tell anybody else how I feel they don't care..." (Macdonald, Sinason & Hollins, 2003, p.441).

Therapy also provided an opportunity for extended conversations which, for some participants, was representative of the distinctive contribution of psychotherapy:

'in hospitals they got a few other people and they only have a short space of time that's it, but here (psychology) I could talk for about an hour' (Gifford et al, 2012, p.117).

The combination of the client's ability to talk freely in extended conversations and the therapist's receptiveness seem to be factors which contributed to the relational depth experienced by participants with their therapist (Pert et al., 2013). Participants across studies also described being encouraged to talk:

"They ask you questions...[Therapist] does speak a little bit, but then she goes quiet after and it's our turn to talk to her" (Macdonald, Sinason & Hollins, 2003, p.444).

Indeed, participants across studies emphasized the ability to talk openly as a dominant factor which facilitated their engagement with psychotherapy (Ramsden et al., 2015). Some participants reflected negatively on instances where their contributions to a discussion were not received in a spirit of receptivity:

"What wasn't helpful was like when the therapist said we already discussed this so let's just stop talking about this because we already discussed [it] (Hassiotis et al., 2013, p.190).

Across studies, participants consistently placed a high value on the absence of boundaries and limitations of what they could discuss:

"I could take all things out without holding back, it was good talking to her. (Khan & Beail, 2013, p.281)

Some participants contrasted the feeling of being safe to talk openly and honestly in one-to-one therapy contrasting with their experience of feeling more guarded and reticent to make disclosures within group therapy:

"Being honest, it's good (...) whereas if you are in the group you can't [be]

(...) Because you've got... loads listening haven't you?" (Pearson et al., 2021, p.288).

One client also appeared to conceptualise open conversation as a necessary tool for maintenance and repair of their relationship with their therapist:

"X was pushing me too hard to make sure I wouldn't do it again. I don't like to be pushed. It made me feel angry like I wanted to punch something, but I was able to talk to X about that openly" (Merriman & Beail, 2009, p.45).

Subordinate theme: Confidentiality & Containment

The private and containing quality of the therapeutic relationship was also an important issue for many participants (Crossland, Hewitt & Walden., 2017; Lewis, Lewis & Davies, 2015; Trustam, Chapman & Shanahan, 2020; Hays et al., 2007; Thomson & Johnson, 2016; Pert et al., 2013). Participants expressed their gratitude that disclosures within the therapeutic encounter would not be shared with others, including family members:

"It's better to talk to people one to one, then you can talk to him about how you're feeling, what your problems are and how you can sort them out without having to talk about them in front of your parents" (Trustam, Chapman & Shanahan, 2020, p.256).

Participants' confidence in confidentiality appeared to generate the trust that is required for genuine relational depth to emerge (Gifford, Evers & Walden, 2012). Some participants did express concern that disclosures may be shared with the wider system, which likewise attested to the notion that confidentiality within therapy is central to the development of the therapeutic alliance (Lewis, Lewis & Davies, 2015). The value attached to confidentiality was particularly evident in group settings and in client cohorts with forensic histories (Hays et al., 2007). Unsurprisingly, some participants expressed their preference for one-to-one session (Thomson & Johnson, 2016), due to their increased confidence in the private quality of one-to-one conversations:

"I felt a bit more comfortable one to one, because you can talk about things that are private and confidential. Any, like...eh problems that you've got that you don't want anybody else to know because it's private, you know" (Pert et al., 2013, p.363).

Other participants placed emphasis on the experience of having their emotions contained, enabling them to achieve a greater degree of emotional stability:

"I was all over the place. I'm definitely in a better place" (Hassiotis et al., 2013, p.190).

Subordinate theme: No threat of negative evaluation

Another theme related to safety was the importance participants attached to not being met with negative responses to their disclosures, a theme which also overlapped with confidentiality. One client, for example, described anticipating a negative response from their therapist:

"I was a bit nervous. I didn't know what to say. I got a bit tight, scared of what he might do to me..." (Merriman & Beail, 2009, p.44).

Another client commented;

"sometimes families don't want to go through details like that with a professional person, so in a way I was glad that she spoke to me because there were issues that I didn't want my family to know" (Gifford et al, 2012, p.117).

Some participants had learned to anticipate negative evaluation and hostility due to experiences of victimisation in their accommodation or when in the community (Trustam, Chapman & Shanahan, 2020), while others placed emphasis on the importance of a non-judgemental ethos (Marwood & Hewitt, 2012). For other participants, anticipating negative evaluations in some instances was due having committed criminal offences; a cohort of participants (Hays et al., 2007) who had committed sexual offences discussed how they kept their forensic histories secret due to a fear of being met with threats or social ostracism:

"It's not the sort of thing I like to broadcast. I don't know the reason why... they'd kill me if they knew. My name wouldn't be Y if they knew what I had done." (Merriman & Beail, 2009, p.44).

A client in another study commented:

"But some people I don't tell because they might take it the wrong way and might beat me up, or, they might call me a pervert or, whatever, you know what I mean?" (Macdonald, Sinason & Hollins, 2003, p. 444).

However, for some participants, concerns about being met with negative responses were more generalised and not explicitly connected to offending behaviour, but were general concerns about being met with mockery, for example being laughed at (Macdonald, Sinason & Hollins, 2003, p. 440) or hostility:

"It's none of that 'you better watch what you're saying'. With (therapist) you can just let it all hang (out)" (Pert et al., 2013, p.363).

Thus, the relief which followed from the absence of negative responses seemed connected to a sense of personal safety within therapy.

THERAPY TASKS

Primary theme: tasks identified

The tasks associated with specific therapeutic modalities and associated goals appeared to be salient aspects of the therapeutic experience for some clients (MacMahon et al., 2015). Some clients referred in non-specific terms to undertaking activities within therapy:

"But if you're doing [CBT] therapy they take you out and make you do [things]" (Hassiotis et al., 2013, p.190).

Participants were able to link tasks to their difficulties, such as specific phobias or emotional processing (Hassiotis et al., 2013). Participants across other studies described possible links between the tasks and their therapy goals, including the acquisition of practical coping strategies such as relaxation techniques or the development of general competencies, though it was not always evident that the acquisition of particular competencies was identified as a goal in advance (Cameron, Swanton & Dagnan, 2020; Lewis, Lewis & Davies, 2015; Gifford, Evers & Walden, 2012). Other participants described acquiring skills which they were then able to impart to others, assuming the role of teachers, with a goal of emotional regulation implicit in the description:

"We're actually allowed to teach the other clients our skills...because it means that everybody can live in a calmer place" (Thomson & Johnson, 2016, p.110). Another participant also implicitly linked their participation in therapeutic tasks to the goal of

emotional regulation:

"[...] role plays which was quite good [...]. We did it in different ways, like in an aggressive way, or a calm way, and to see how people react when you do it in an aggressive or calm way" (Stenfert Kroese et al., 2016, p.305).

Others found it difficult to identify links between the goals towards which they had worked with their therapist and the specific tasks undertaken during therapy. For example, one client felt that while their threat response had lowered to more manageable levels, the link between this outcome and therapeutic techniques seemed unclear:

"Um I just feel different I don't know why I think (the therapist) helped me a lot with the breathing and the room I don't know 'it just felt like a weight lifted off my shoulder...so when I was walking down the road with the kids I just felt, I don't know, that no one would harm me kind of thing..." (Hardiman et al., 2018).

Primary theme: Lack of clarity on therapeutic tasks

Some participants experienced difficulty in attempting to recall specific aspects of CBT or DBT such as homework tasks (Thomson & Johnson, 2016), while others described difficulties in understanding the core components of CBT (Hassiotis et al., 2013) and abstract DBT concepts (Crossland, Hewitt & Walden., 2017), as well as difficulties in implementing them (Thomson & Johnson, 2016). One client stated:

"Mm...I think it's good, mm it's a bit, I am losing track of it now, I don't know what I am doing and I am just writing anything down..." (Roscoe et al, 2015, p.269).

In other therapeutic modalities, such as compassion focussed therapy, the particular tasks of concepts of CFT did not emerge as an obvious theme within client experiences. Participants instead placed emphasis on interpersonal factors, such as the ability to form genuine friendships with other participants (Croom et al., 2021; MacMahon et al., 2015), the therapist's calm disposition, the therapist being "kind and very patient" (Croom et al., 2021) and their ability to listen (Hardiman et al., 2018). Others commented on their difficulties processing or recalling information associated with specific tasks:

"I do struggle with my memory. It's really hard to remember in the situation what to do. Relevant to goals and tasks (Ramsden et al., 2015, p.248).

Another commented:

"She talked to me in drabs and talked too fast. I could only understand half the time" (Khan & Beail, 2013, p.281).

Another client reflected on the inaccessibility of some tasks within therapy due to their difficulties in processing and assimilating information:

"So if it was split up a bit and so you've got chance to sort of explain it, and sort of go through it easily, steps or baby steps for me would be a lot easier than too much information, it makes your head fried then" (Stenfert Kroese et al., 2016, p.306).

Other participants found it difficult to describe specific tasks they had undertaken during therapy or understand the cohesiveness between sessions, viewing therapy instead as a series of discrete, unrelated encounters (MacMahon et al., 2015).

Primary theme: Collaboration and personal agency

Participants across studies placed emphasis on the collaborative nature of the relationship with their therapists (Cameron, Swanton & Dagnan, 2020; Pearson et al., 2021; Pert et al., 2013; Lewis, Lewis & Davies, 2015):

"But then you got to help yourself. You have got to put in practice what you have learnt from the psychologist. If you don't do that it is a waste of time going (Lewis, Lewis & Davies, 2015, p.450).

"I can work with her and tell her things and that. Yes; working and that with her, like working with her and that; I can work with her" (Lewis, Lewis & Davies, 2015, p.451).

Participants also reflected favourably on sessions characterised by flexibility, with instances of client-led sessions evident:

"[the therapist] would play it by ear, depending on what I wanted to talk about and what I didn't want to talk about" (Pearson et al., 2021, p.290).

The willingness of therapists to be adaptive was also linked by some participants to the Rogerian notion of accurate empathy, whereby the therapist is appropriately attuned to their emotional cues:

"...It's like she knows if you're sad, she knows if you just want to sit there and be quiet, she'll just sit there and be quiet" (Pearson et al., 2021, p.290).

For other participants, the spirit of collaboration was implicit in their descriptions, with participants in one study commenting favourably on being treated as an 'equal' or 'like an adult', often contrasting to their experiences of being 'treated like a child' within other contexts (Pert et al., 2013, p.363). Other participants described developing abilities relating to interpersonal effectiveness and assertiveness:

"I can now speak up more' and 'I've been more assertive really, you know?" (Gifford, Evers & Walden, 2012, p.118). Other participants described their efforts to self-advocate and effectively articulate their needs. Two participants reported that when they encountered new concepts/skills which were difficult to understand, they confidently asserted this:

"I said "what we will have to do is try and explain it to me again". So, they explained it to me again in more detail but slowly for me" (Pearson et al., 2021, p.287).

Another stated:

"if there is anything that you don't understand (...) now we are so upfront, we will just say to them, 'can you talk in English please?" (Pearson et al., 2021, p.287).

Participants in other studies identified difficulties they and their therapist had worked through in a fashion whereby the participants actively participated, rather than adopting a passive relational style:

"I got up and done all the drawings on the whiteboard (...) And the writing on the whiteboard (...) I asked if I could get up and do some writing" (Pearson et al., 2021, p.287).

Similarly, a client from another study commented on the importance of a motivation and commitment to voluntarily engage with their therapist throughout psychotherapy:

"you have got to choose to work with them, or don't work with them" (Roscoe et al, 2015, p.272).

Another client described the importance of qualities such as perseverance and gratification postponement, again attesting to the individual responsibility numerous participants appeared to assume:

"Got to grin and bear it for the first few weeks then you may find it do come easier, you may find it do not come easier but you still got to grin and bear it" (Lewis, Lewis & Davies, 2015, p.448). Another client noted the importance of individual responsibility, stating:

"I soon realized that I needed support. I needed help basically...I was ready to do the things that I needed to do" (Ramsden et al., 2015, p.250).

For a number of participants, a greater sense of autonomy and independence was an explicit or implicit goal, though it was not always clear how this was linked to therapeutic tasks. One participant described their goals thus:

For me to get a job... get my own place all that kind of stuff and say be a better person (Trustam, Chapman & Shanahan, 2020, p.257).

Other participants appeared to have acquired meta-competencies, whereby they assumed the role of agent of change and identified their need to assume personal responsibility to improve their lives by actively engaging with the content of psychotherapy:

"Well, it's not really what she (the psychologist) can change, it's mainly what I can change, I mean she can give me all the advice in the world cause virtually that's what she was doing but it was up to me to take on board what she was saying and do something about it myself, so it was all about me" (Gifford, Evers & Walden, 2012, p.118).

THERAPY GOALS

Primary theme: Goals identified

Across studies, it was not always clear whether goals were directly linked to therapeutic tasks. In one study (Cameron, Swanton & Dagnan, 2020) participants acknowledged the collaborative process of identifying goals with their therapist. Some participants also described therapy as facilitating personal development helping to instil a sense of optimism about the future, with specific goals relating to personal agency:

"I know I had to do this if I wanted to get anywhere in life. So, I had to see (psychologist)...because I want to move out. I want to get my own little place. I want my independence back. I know now in the future I am not [making] the same mistake again" (Lewis, Lewis & Davies, 2015, p.449).

Other clients had specific similar goals relating to relating for example to discharge from services employment or housing (Roscoe et al, 2015). However, for other participants, goals were sometimes phrased in a broader, non-specific terms, with one participant expressing goals in the following terms:

"Um, making me feel happier at home to make me think more for myself" (Gifford, Evers & Walden, 2012, p.118).

Other participants identified broader goals such as a desire for positive changes in relationships and to experience more social opportunities. For example, one study (Pert et al., 2013, p.364) listed goals identified by participants in the following terms:

"Change the way others see me; To do things for myself; Feel better about myself; To get a job; Build my confidence; To get something to do; Stop letting things get to me; To get out more; and Stop being aggressive; meet new people; Express myself better; To make friends."

Primary theme: Post-therapeutic change: Implicit goals

Across studies, participants described a broad range of outcomes associated with therapy (Merriman & Beail, 2009; Roscoe et al, 2015; Trustam, Chapman & Shanahan, 2020; Gifford, Evers & Walden, 2012; Marwood & Hewitt, 2012; Pearson et al., 2021; Lewis, Lewis & Davies, 2015; Cameron, Swanton & Dagnan, 2020). In the current data, goals were not always easily distinguishable from outcomes. The current sub-ordinate theme highlights instances where the goals and outcomes were closely linked as to not be able to confidently express them as separate constructs.

Participants often attributed positive changes in their behaviour, emotional wellbeing or beliefs about the future to their experience of therapy: "I was really down at the beginning. I was bottling everything up and couldn't cope with it. It's different now... Everything was going wrong. That's all changed now" (Merriman & Beail, 2009, p.45).

Participants across studies tended to describe such outcomes without necessarily clarifying whether these were goals identified at the commencement of therapy, or outcomes which spontaneously emerged during the course of therapy. For example, some participants reported experiencing more gratifying social interactions following therapy, and emphasised improvements in their interpersonal relationships. A greater feeling of acceptance was seen as an important aspect of recovery (Stenfert Kroese et al., 2016). One client commented:

"I think the difference is I can talk more, I can talk to people a bit, a bit better—like my friends ..., which is now. I think, back in the past it was more difficult for me to talk to anyone" (Trustam, Chapman & Shanahan, 2020, p.257).

This may imply that some clients had goals relating to social integration and being more assertive during interpersonal communication. Another client expressed an ongoing wish to "*be a better person*" and a belief that "*things can get better*" (Trustam, Chapman & Shanahan, 2020, p.257), implying general, non-specific goals relating to personal development and experiencing a greater sense of wellbeing. Another client stated: '*I got my confidence back*' (Gifford, Evers & Walden, 2012, p.118), implying the existence of implicit goals relating to anxiety management or developing a greater sense of positive self-regard.

Other participants commented on how the therapeutic relationship and therapeutic processes had a transformative impact. One particular example may suggest a client had implicit goals specifically related to reducing the frequency of intrusive memories, developing a greater sense of confidence and optimism about the future:

"Yes. The past was gone from my head; (psychologist) has helped me to remove the past from my head, she has changed my life, she has helped me to have

more confidence, I don't suffer any nightmares, I used to have. I used to get really bad nightmares the time I had the past in my head. I actually felt good about myself, I actually felt excited about myself; I actually felt that all my dreams have finally come true. Things (psychologist) helped me, was enough to make me feel really excited and make me feel more excited about living and looking forward to the future" (Lewis, Lewis & Davies, 2015).

THE ALLIANCE IN CONTEXT

Primary theme: Therapist as advocate and problem solver: extending the relationship into the client's wider context.

Some participants described their psychologist as acting in a bridging and coordinating capacity, to ensure they received appropriate care from within their wider support system. This suggests that, some participants conceptualised the therapeutic remit as extending beyond their individual therapy sessions and encompassing activities beyond any specific therapeutic modalities:

"If I had a problem with anything I would just ring her and she would get back to me and help me get in touch with the right people to sort it" (Ramsden et al., 2015, p.253).

Participants in other studies likewise recalled how their psychologist would act in a coordinating capacity, attending meetings with others within their support system, including staff and family members:

"They would have big meetings with the staff... When we finished, she asked me to go and get my mum" (Lewis, Lewis & Davies, 2015, p.449).

Another recalled:

Another participant described how their psychologist had liaised with their wider support system to identify a strategy to help ensure safety and manage risk-taking behaviours: "I text staff and asked them to call me and they will call me and we will have a certain time to go out and they will call me within that hour to see that I'm safe" (Gifford, Evers & Walden, 2012, p.118).

Participants experienced such extra-therapeutic tasks and systemic involvement as a facilitator of therapy and an important aspect of the support they received. Indeed, some participants expressed a wish for a more prescriptive relationship with their therapist. For one client, an expectation for a prescriptive relationship was present at the outset, resulting his disengagement in psychotherapy prematurely:

"I ended my sessions with the psychologist as I didn't think she knew the answers for the questions I asked her. I was a bit annoyed that she didn't know the answers to" (Gifford, Evers & Walden, 2012, p.118).

Another client from the same study wished that their psychologist would:

"not ask so many questions and advise me a bit more" (Gifford, Evers & Walden, 2012, p.118).

Another client described a somewhat passive relational style, in which the therapist solved their problems, rather than helping the client develop problem-solving skills:

"X sorts my problems out. I've had problems the last three weeks and he wrote them down and sorted it out. I leave it to him to sort things out" (Merriman & Beail, 2009, p.44).

Themes not in the framework

Remaining themes that had implications for alliance are now briefly discussed, with full theme descriptions included in appendix B. Themes could be seen as precursors or necessary building blocks for alliance. The theme of *'other non-specific factors'* describes general, non-specific comments about the therapist while further theme of *'sadness due to*

endings' also emerged. Therapy endings are a part of the therapeutic process for all client groups, but which may be particularly challenging for people with ID (Dunn et al, 2023).

Quality Appraisal

The CASP checklist criteria was used to ascertain the strength and limitations of the studies included in the current review (see Appendix C). The CASP does not contain a standardised scoring system by which one can determine whether a study is of "high" or "low" quality. Thus, the current study used the same scoring thresholds used by Evans and Randle-Philips (2020) to determine study quality. Overall, the included studies were of a high quality (all original studies scored > 7), suggesting all original studies used appropriate methodologies and that the results were reliable and relevant to the research questions. The overall high study quality increases confidence in the reliability of the current findings.

Discussion

This study examined whether Bordin's model (1979) was suitable as a "best fit" framework when describing the therapy experiences of people with ID. Consistent with Cameron, Swanton & Dagnan (2020), the current study suggests that therapeutic processes, as experienced by those with ID, can be broadly understood within Bordin's (1979) framework. The bond was particularly central to client's experience, an emphasis which is not necessarily reflected in Bordin's model but seems particularly relevant to the experience of people with ID. The bond was formulated as having three components: trustworthiness, the distinctiveness of the bond, and its safety. Safety also comprised three subthemes: open talking, confidentiality, and no fear of negative evaluation. Tasks were also identified as an important aspect of client experiences though participants often expressed a lack of clarity with respect to therapeutic tasks and the content of therapy sessions. A theme of collaboration and personal agency also emerged and was incorporated into the *a priori* task component of Bordin's model. Goals were judged to be less well differentiated in the data. While some data relating specifically to goals could be incorporated into Bordin's model, clients often discussed therapy outcomes instead. These data therefore suggest that, at least for some clients, therapy had a specific direction and trajectory and was aimed towards something, though it is also possible that progress emerged for some clients as a spontaneous by-product of interpersonal engagement. A judgement was made to incorporate these data within a subtheme of implicit goals. Finally, an additional theme of the therapist as an advocate and problem solver was identified. This theme could not easily be accommodated in Bordin's *a priori* categories. This suggests Bordin's model may need to be expanded to account for the social and interpersonal context of ID, with some participants requiring their therapist to assume a proactive stance with respect to advocacy, coordinating, and problem solving.

Many of the therapeutic processes highlighted in the current study are relevant to broader considerations of the context of the lives of people with ID. For example, safety, and the confidence that disclosures could be made safely within therapy, was an overarching theme for people with ID. Though personal safety is widely recognized as central to psychotherapy (Podolan & Gelo, 2023), an emphasis on safety makes particular sense within the broader social context of ID, as this demographic is likelier to experience rejection, stigmatization and victimisation (Dagnan, & Waring, 2004). Safety was also substantially associated with themes such as containment and confidentiality and the *removal of the threat of negative evaluation*, rather than an exclusive wish to be positively received. Safety, may thus be central to what bond represents. The themes of open talking, confidentiality, and minimizing the risk of negative evaluation within therapy may develop the present understanding of bond, which was described in general and non-specific terms by Bordin (1979).

These themes seem consistent with Baumeister and Tice's (1990) suggestion that a basic aspect of human psychology is the need to be integrated into a social group, an insight

which helps explain why concerns about stigma and personal safety may be particularly important to people with ID. It has been plausibly hypothesised that overtly negative judgements about a person's behaviour or character are distressing as they activate archetypal fears and concerns linked to rejection, abandonment, isolation and shame (Gilbert, 2010), experiences to which people with ID are particularly vulnerable. Indeed, participants across many studies described making disclosures in therapy of an intensely private nature, about which they felt guilty or ashamed, or which had previously resulted in negative social responses outside of the therapeutic setting (Macdonald, Sinason & Hollins, 2003; Merriman & Beail, 2009; Hays et al., 2007). The innate desire to be socially integrated may explain why, in the current study, client anxieties were often focussed on matters relating to social acceptability and why individuals described feeling highly guarded when disclosing issues such as antisocial or criminal conduct, particularly within group settings (Macdonald, Sinason & Hollins, 2003). Indeed, some participants described refraining from making disclosures to both family members and within group settings, for fear of causing distress, harming their reputation, or being met with negative social evaluation. Such anxieties illustrate that the general experience of anxiety is not confined to the specific moment of social exclusion. Rather, participants often described how they had learned to anticipate negative social responses following previous experiences of peer victimisation, negative responses following self-disclosures, or requests for support being ignored (Stenfert Kroese et al., 2016).

There was also a strong overlap between many of the themes relating to Bordin's core *a priori* categories. For example, it was often difficult to determine how themes relating to task and goal could be strictly distinguished from the interpersonal bond. Bordin implicitly acknowledged the substantive overlap between tasks and interpersonal processes, for example defining tasks as encompassing "*empathic understanding, communicating,*

interpreting [and] self-disclosing" (1979, p.254). Such an overlap was evident throughout the current study. The emphasis participants placed on the relational and interpersonal aspects of therapy, such as open discussion and being listened to, seems consistent with Bordin's definition of tasks, though the current study may offer further insights into how the conceptual understanding of *talking as a task* can be developed. For instance, participants placed particular emphasis on the general process of talking openly about their difficulties and being received in the spirit of receptivity, with the original authors of one study suggesting that open talking, in and of itself, characterises therapy (Macdonald, Sinason & Hollins, 2003). Participants also placed emphasis on qualities such as the ease and openness of conversations, and the experience of being received in a spirit of receptivity. Indeed, an instance where a therapist appeared to prioritise a manualised schedule at the expense of a client's contribution was experienced negatively: "What wasn't helpful was like when the therapist said we already discussed this so let's just stop talking about this because we already discussed [it] (Hassiotis et al., 2013, p.190). Thus, while talking appeared to be a task which supported therapeutic change, the conceptual understanding of *talking as a core* task may be expanded to encompass the qualities of openness and receptivity, a finding consistent with Kaiser's emphasis on the importance of therapists relating to clients in a spirit of receptivity (2012). The current findings also suggest talking supports therapeutic change when it occurs within a context of a temporally stable relationship characterised by interpersonal trust, containment, and consistent displays of affective concern for the client's welfare.

There were additional indications that tasks and bond may be inextricably connected. Some clients described how the experience of having someone consistently attending to their difficulties conveyed a sense of genuine care and presence, while also validating them as someone who possesses intrinsic value, with a distinctive contribution deserving of

consideration: "I felt like an actual person who had the right to tell someone how he feels and not feel daft" (Stenfert Kroese et al., 2016, p.303). This highlights the complexity and depth of the therapeutic encounter, and the difficulty in parsing client experiences into discrete categories.

The collaboration experienced by some participants and the development of competencies often implied a sense of personal agency, a discovery of self-assertion, and an expansion of competencies. Some client described experiencing a novel capacity to influence the course of their lives (Huber et al., 2021). Several examples attest to the presence of this theme, with one particular example illustrative of participants intentionally influencing processes relating to psychotherapeutic change: "I can now speak up more' and 'I've been more assertive really, you know?" (Gifford, Evers & Walden, 2012, p.118). Another client described a degree of self-assertion which implied an equity in the therapeutic relationship and skills related to interpersonal effectiveness: "X was pushing me too hard to make sure I wouldn't do it again. I don't like to be pushed. It made me feel angry like I wanted to punch something, but I was able to talk to X about that openly" (Merriman & Beail, 2009, p.45). This finding appears noteworthy, given that ID is defined by a limited ability to live independently and autonomously. Though relating to participants in a more challenging style, as described in this example, is likelier to lead to ruptures in the therapeutic relationship, research suggests that positive therapeutic outcomes are closely associated with the client and therapist successfully repairing such ruptures (Safran et al., 1990). Though this research is based on data from mainstream populations, the data in the current study relating to autonomy and self-assertion highlights the broad range of abilities possessed by people with ID, and suggests that the principle of individual responsibility within Bordin's model is to some degree compatible with the experiences of at least a subset of the people with ID who access psychotherapy.

Some participants across multiple studies found some of content relating to therapeutic tasks and specific modalities to be inaccessible. This naturally speaks to the need for reasonable adaption for people with ID, a finding which converges with previous research which highlights the need to reduce the complexity of therapeutic techniques for clients with ID by reducing the quantity of written materials and presenting simplified formulations (Kellet et al. 2015). It is unclear from the current data whether inaccessible therapeutic content interfered with alliance formation, from the perspective of participants with ID. One could argue, from Bordin's perspective, that alliance formation, by definition, is undermined if aspects of therapeutic content and tasks are inaccessible.

Likewise, with respect to goals, it was often unclear whether the participants' goals were always foreknown or collaboratively agreed upon within initial therapy sessions, or whether positive changes emerged as a spontaneous by-product of therapeutic engagement. Goals identified by participants were sometimes quite broad and non-specific and it was not immediately evident how such goals could be deconstructed into actionable sequences of tasks. When considering the difficulty in clearly differentiating goals in the current data, it is perhaps significant that participants across studies described the therapeutic relationship as highly impactful and transformative (Gifford, Evers & Walden, 2012; Cameron, Swanton & Dagnan, 2020; Hardiman et al., 2018; Pert et al., 2013; Lewis, Lewis & Davies, 2015). Clients seemed to view the relationship as a genuine relationship in and of itself rather than a relationship which served the primarily instrumental functions of facilitating engagement with goals and tasks. This may imply that a foremost therapeutic outcome for some participants was experiencing the impact of a supportive relationship, and that participants may have had implicit goals related to interpersonal factors, such as having a continuous experience of being listened to, feeling valued, and understood. Though interpersonal relationships were seldom stated as formal therapeutic goals, strong bonds may have emerged as a by-product of therapeutic processes, and then retrospectively been identified as a therapeutic outcome of primary importance once participants experienced the value and transformative quality of that relationship. Therefore, the bond may not merely represent a foundational component of the therapeutic alliance but may also represent an emergent and implicit goal or outcome for some clients, rather than one which was consciously articulated or mutually agreed. Goals relating to other aspects of the client's life may then have organically emerged during the course of therapy. Such a speculation is consistent with Bordin's observation that some therapeutic modalities may require an extended temporal component whereby tasks and goals are *discovered* and emerge organically within the context of dialogue between client and therapist (1979).

Overall, clients appeared to place considerable emphasis on the interpersonal aspects of therapy. It seems reasonable that those who may lack the experience of interpersonal connectedness will ultimately place more emphasis on the novel experience of an empathic and supportive relationship. Therapists, by contrast, may place more emphasis on a short-term piece of work defined by goals and tasks. As Yalom (1989) previously observed, the therapeutic relationship is likelier to assume an importance and centrality to the life of a client in a way that it will not become central for a therapist. While therapists have multiple clients, clients are likely to have only one therapist. For those people who are more socially isolated, as if often the case for people with ID, this relationship may assume a particular centrality in their lives. This appears to be *the* fundamental and inherent asymmetry in the client-therapist relationship, and it may be implausible to expect any one model of the therapeutic alliance to comprehensively capture the perspectives of both client and therapist when the relationship has this profound asymmetry at its heart. Thus, though a recent study concluded that Working Alliance Inventories based on Bordin's model can reliably measure the alliance with clients from ID, the study ultimately reflected the perspectives of healthcare

professionals (Oudshoorn et al., 2023). Likewise, Bordin's original model reflects a professional's perspective on the alliance, formulated within the context of broader professional concerns about the practise of psychotherapy. The current results suggest that client perspectives suggest as greater interrelatedness between bonds, tasks and goals, and an expansion of the concept of goals to encompass both emergent goals and implicit goals relating to interpersonal connectedness. This observation may have particular implications for endings when working with this client group (Appendix B).

Finally, the experiences of a significant number of participants suggested they required increased support to exert meaningful change in their lives. The concept of alliance may thus need to be broadened to reflect how the social context of ID may open other aspects of the relationship, whereby therapists support the client's tasks and goals by assuming a proactive stance with respect to advocacy, problem solving, and coordinating with the client's wider support network. Indeed, prior reformulations of the alliance have acknowledged the broader context in which the alliance occurs as an important dimension which may not be fully described within Bordin's model (Ross, Polascheck & Ward., 2008). Concerning the current study, one original author reflected on how ID may predispose people to developing more dependent relational styles with their therapist. As Pert et al., (2013, p, 365) state: "...some clients seemed to feel that they required a long-term supportive relationship. They seemed to have an external locus of control with regard to their emotional difficulties or feel they could not maintain progress made in therapy." Likewise, Merriman and Beail (2009) commented that when clients were asked about their experience of therapy, a sense that they were dependent upon the therapeutic relationship emerged. Such observations reflect a principle focus on autonomy, which is central to mainstream psychotherapy, and perhaps a cultural bias from an individualistic culture (the UK) in which ideals such as "individual autonomy", independence and self-reliance are prioritised politically and socially (Triandis,

2001). However, assuming a wider therapeutic remit with respect to advocacy, problem solving, and coordinating with the client's wider support network is likely to be proportionate and necessary for some people with ID given their social and developmental context. Those whose lives are characterised by disempowerment and a lack of autonomy and interpersonal support are likelier to require pro-active support to establish meaningful change in their lives. Concerns about dependency could also be framed within the context of the findings of Holt-Lunstad and colleagues (2015) which highlight the extent to which interpersonal connectedness and meaningful relationships are generally essential. Interpersonal dependency, therefore, is a necessary component of psychological and physical wellbeing, rather than a specific need which characterises the experience of people with ID.

Summary

This is the first study to apply Bordin's model (1979) to the experiences of clients with ID accessing psychotherapy, within a qualitative meta-synthesis, and may indeed be the first application of this methodology to Bordin's model within any client group. The current study identified broad areas of client experience which are consistent with Bordin's model, particularly the centrality of the bond, though the weight clients assigned to the interpersonal bond appears to be greater than is implied within Bordin's original formulation. The superordinate theme of safety, with subordinate themes of open talking, containment, and confidentiality were also identified as components of bond, and may have helped to develop the conceptual understanding of this construct. Tasks were also a salient aspect of client experience, though a number of clients found therapeutic tasks associated with various modalities to be inaccessible. Goals were likewise an important aspect of client experience though it is possible that goals were an emergent property of the therapeutic process and that clients also had implicit goals relating to interpersonal connectedness. Notably, themes emerged relating to autonomy and independence, however these themes did not characterise

the experience of all clients. A number of clients had self-described or implicit difficulties with respect to independence and autonomy, and many clients described difficulties understanding therapeutic content. These results reflect the broad range of abilities and cognitive functioning within ID. Consequently, Bordin's model may not entirely accommodate the social context of ID which is crucial for understanding how bond, tasks and goals may be experienced for those clients with ID who experience a lack of autonomy and agency in their lives. The broader context of ID may require therapists to appropriately balance goals relating to independence and autonomy against the need to assume a proactive approach to advocacy and problem solving on behalf of clients with ID.

Limitations

There are several limitations associated with this study. There was an overall lack of consideration across studies as to whether the researcher-participant relationship may have impacted upon the findings. This absence seems particularly noteworthy given the social context of ID described above. An additional limitation is that all studies included in the current review were from the UK potentially limiting the generalizability of the current findings.

It is also well-established that qualitative research can generate themes based on the pre-conceptions or research interest of the researcher (Cohen et al., 2007). The questions being asked in the original studies included in the current review were often not related to the alliance. Had researchers in the initial studies framed their enquiries within Bordin's tripartite model, participants may have emphasised aspects of their experience that correspond closely with Bordin's model. Indeed, the sole study which specifically examined the applicability of Bordin's model to participants with ID observed that their experiences of the alliance could be accurately comprehended through this framework (Cameron, Swanton & Dagnan, 2020). However, the emergence of themes relating to bond, goal and task across a range of studies

may attest to the generalisability of Bordin's model, rather than merely being a research artefact.

The current synthesis also integrated the experiences of participants receiving both individual and group psychotherapy. The way alliance functions within group-based and individual therapy may of course be distinct in certain respects. However, there is good reasons to think that including both individual and group-based psychotherapies is worthwhile, namely that Bordin's model has previously been utilised to examine multiple interpersonal systems (Pinsof, 1988; Pinsof & Catherall, 1986). Lastly, the current study lacked access to the original qualitative transcripts. The current synthesis therefore represents an interpretation of what was deemed relevant and salient by prior researchers. The current study sought to mitigate the inability to test the credibility of its findings against the original data by rigorously discussing and cross-examining the credibility of the theme structures which were identified.

Future research and clinical implications

The current findings suggest that the context of ID is sufficiently important in understanding the nature of the therapeutic relationship and entails activities from the therapist that are not typical for therapists in mainstream mental health settings. Specifically, a focus on autonomy and personal responsibility needs to be appropriately balanced against advocacy for, and problem-solving on behalf of, participants with ID. Advocacy and problem solving may constitute a sufficiently distinctive element of therapy as to not be immediately subsumed within the bond, goal, and task framework and are clearly activities that the therapist undertakes as part of their relationship with the client with intellectual disability. Future research could consider exploring the concept of pro-active advocacy on behalf of a client to determine if it represents a novel dimension to Bordin's model.
The current findings also suggest that it is possible that clients and therapists may have different perspectives of the therapeutic relationship, with clients placing greater emphasis on interpersonal and process factors. Future research is needed to determine whether interpersonal aspects of therapy are more central to the experiences of people with ID, or perhaps whether there are common factors, such as disempowerment and social isolation, which predict whether clients are more likely to assign more weight to the interpersonal aspects of therapy.

Lastly, participants in the original studies were selected based upon being cognitively able to participate in interviews and articulate their experiences. Participants with more profound disabilities, including those who are nonverbal, are generally under-represented in clinical research (Beail 2010), and are also less likely to be offered psychotherapy. Analysing therapeutic processes for clients who are less verbally able, and considering what that alliance means in this type of interaction, is interesting but undoubtedly highly challenging.

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Chapter Three

Bridging Chapter

Word count: 524

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Bridging chapter

The utility of analysing phenomena using categories was discussed in the introductory chapter. Grouping information into discontinuous categories can be a particularly useful and explanatory method, for example in highlighting the distinctive impairments and needs of specific clinical populations, such as those with ID. There are also specific ways in which those with ID are more vulnerable relative to the mainstream population, due to the intrinsic qualities of intellectual impairment and the social content of ID (Gilmore & Cuskelly, 2014). Considering people with ID as a distinctive clinical population is therefore helpful in some respects. However, thinking in categories can also obscure profound areas of similarity and convergence between apparently different groups. The historical examples and empirical literature cited in the introductory chapter, as well as the findings of the qualitative metasynthesis, appear consistent with the belongingness hypothesis proposed by Baumeister and Tice (1995). Indeed, there is a weight of evidence to suggest that the need for interpersonal connectedness may be so profound as to constitute a central intrinsicality of human nature. The meta-synthesis undertaken in chapter two appears broadly consistent with this thesis, showing that people with ID principally attached value to the interpersonal aspects of psychotherapy, particularly the patient-therapist relationship. Furthermore, many factors in the lives of those with ID such as social isolation, victimisation, and an absence of supportive interpersonal relationships (Gilmore & Cuskelly, 2014) may contribute to a distinctive experience of the therapeutic relationship, whereby the therapeutic relationship takes on a centrality in the lives of people with ID. Further research is, of course, needed to determine whether the interpersonal aspects of therapy indeed assume primacy for people with ID, and to what extent this is similar or dissimilar to trends within the mainstream clinical population. While the present findings suggest that the relationship, from the perspective of participants,

was a genuine relationship and therefore did not serve a primarily instrumental function, the relationship appears to be inextricably associated with the technical aspects of therapy in a way which is difficult to parse, or model and describe in a generalised manner.

The issue of how people with ID experience the therapeutic alliance represents one aspect of a broader, overarching clinical issue central to this thesis; how do the intrinsic qualities of disability, and the social context of disability, affect how people with ID experience therapeutic processes and to what extent does ID and its social context change the key variables associated with mental health outcomes? When determining the extent to which mainstream therapies require adaptation for people with ID, it is necessary to better understand the ways in which the experiences and needs of people with ID converge with, and are distinct from, mainstream clinical populations. To further investigate the underlying processes that affect mental health outcomes for people with ID, and elucidate the areas of convergence and distinctiveness with respect to the mainstream population, this thesis will now undertake an empirical study. The study will examine whether the factors which predict recovery for people with ID accessing IAPT services are equivalent or different to those factors which predict recovery for people from the mainstream population. Chapter four

Empirical paper

Examining the factors associated with recovery for clients with and without intellectual disabilities accessing IAPT services.

Prepared for submission to 'PLOS ONE' 4

Word count: 11247 (excluding references, tables and figures)

⁴ See Appendix XX - XX for author guidelines. For ease of reading, figures and tables are provided within the main body of text

Examining the factors associated with recovery for clients with and without intellectual disabilities accessing IAPT services.

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Abstract word count: 299

Text body word count: 11656

Tables: 3

Figures: 0

Abstract

Background: Mental health services in the United Kingdom (UK) aim to provide equitable access to psychological therapies recommended by the National Institute for Health and Care Excellence (NICE). NICE guidance suggests adaptations to standard psychotherapeutic interventions may be necessary when working with clients with ID experiencing mental health problems. It is therefore helpful to examine whether the factors associated with recovery for people with ID are similar or dissimilar to those associated with recovery for mainstream clients.

Methods: Data from the Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust IAPT service (n=81,216) was analysed. Two groups were matched according to age, gender, referral year, baseline GAD-7 and Baseline PHQ-9 scores (LD, n = 125; non-ID, n=125). T-tests for continuous variables and chi-square for dichotomous variables were used on both matched and un-matched groups to determine the accuracy of the matching process. The impact of predictor variables on recovery for individuals in the matched groups was then explored through logistic regressions.

Results: Amongst unmatched groups, 47.7% of people without ID recover while 35.9% of people with ID recover. However, recovery rates are almost identical following matching (35.4% of people without ID recover while 36.2% of people with ID recover). Logistic regressions further showed that the total number of sessions and disagreement on discharge were associated with recovery outcomes for both ID and non-ID groups. Results further showed that baseline GAD-7 score, social deprivation, referral duration and wait to second treatment were specifically associated with outcomes for people with ID.

Conclusions: There are common factors which predict recovery for both people from the general population accessing IAPT and those with ID. However, there are also factors

which only predict recovery for people with intellectual disabilities. Further research is required to determine whether these findings can be replicated across a larger sample.

Keywords: Intellectual disability; intellectual disability; IAPT; adaptation; mental health; recovery

Introduction

It is well established that people with intellectual disabilities (ID) have poorer health outcomes and experience greater physical and mental health inequalities compared to the general population (Krahn, Hammond, & Turner, 2006). People with ID may also be likelier to develop affective disorders such as depression and anxiety (Hsieh, Scott, and Murthy, 2020), though determining the prevalence of affective disorders amongst people with ID with any degree of specificity remains difficult. Prevalence estimates for depressive disorders range from 2.2% to 15.8% (Cooper et al., 2015; Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Deb, Thomas, & Bright, 2001; White, Chant, Edwards, Townsend, & Waghorn, 2005), while the prevalence of anxiety disorders, though less well researched, is estimated to range from 3.8% to 17.4% (Reid, Smiley, & Cooper, 2011). By comparison, a recent study of the prevalence of probable depressive disorders amongst a UK cohort (n=17,152) suggested a prevalence of 7.5% (de la Torre et al., 2021), while the prevalence of anxiety in the UK has been estimated at 7.2% (Archer et al., 2022). However, Hsieh, Scott, and Murthy (2020) have suggested that estimated prevalence rates for people with ID are likely to be underestimates, due to diagnostic challenges in this population (McBrien, 2003; Perez-Achiaga, Nelson, & Hassiotis, 2009).

The relationship between ID and affective disorders is undoubtedly complex. The core impairments of ID – impaired general intellectual functioning and a reduced ability to cope independently – may interact with common social factors associated with ID, such as a lack of supportive relationships, higher levels of interpersonal estrangement, the experience of victimisations and stigmatisation, and lower socio-economic status (Gilmore & Cuskelly, 2014), resulting in a concomitant increase in mental ill-health. Paradoxically, research suggests that uptake of mental health services by people with ID (Dekker & Koot, 2003; McCarthy & Boyd, 2002) falls significantly short of the prevalence of mental ill-health

(Cooper et al., 2007; Einfeld, Ellis, & Emerson, 2011; Morgan, Leonard, Bourke, & Jablensky, 2008). This may be attributable the variety of barriers faced by people with ID, including organisational barriers and those relating to service availability and quality (Whittle et al., 2018).

There has also been an increased interest in psychotherapeutic outcomes for people with ID, and the ways in which mainstream psychotherapies require adaptation to be made more accessible. Current research suggests that people with ID can benefit from psychotherapies that are adapted from mainstream approaches, such as CBT (Tapp et al., 2023), though people with ID appear to experience poorer treatment health outcomes relative to the mainstream population. For example, National Health Service (NHS) Talking Therapies (Previously Improving Access to Psychological Therapies; IAPT), which forms part of England's National Health Service (NHS), provides evidence-based psychological therapies primarily for people with mild to moderate depression and anxiety disorders. National NHS Talking Therapies data suggests that people with ID experience poorer recovery rates – as defined by NHS Talking Therapies – than people who do not have ID (Dagnan, Rodhouse, Thwaites, & Hatton, 2022). It is important to note that this study uses an IAPT code for 'learning disability' which has doubtful, or at best unknown, validity. There is thus a need to further examine psychotherapeutic outcomes for people with ID and better understand the factors which contribute to these outcomes.

Current research gaps/aims

Mental health services in the United Kingdom (UK) aim to provide equitable access to psychological therapies recommended by the National Institute for Health and Care Excellence (NICE) to people from all sectors of the community. Guidance regarding best practice in working with people with ID and mental health problems was issued by NICE in England (National Institute for Clinical Excellence, 2016). This guidance suggests that a

range of adaptations might be adopted to the standard delivery of CBT interventions. Such adaptations might include changes to content, structure, focus, pacing and duration of therapy sessions, as well as the use of adapted materials and techniques. The IAPT Manual (National Collaborating Centre for Mental Health, 2020) discusses these issues and identifies the need to adapt processes to meet the needs of disadvantaged populations, and specifically recommends that services should provide effective psychological interventions to people with ID (Department of Health, 2009); and recent IAPT best practice guidance describes service approaches to supporting therapy for people with ID (Dagnan et al, 2015). There is thus considerable interest and a growing body of research into how people with ID use and experience mainstream mental health services. Policy in the UK suggests that people with ID and mental ill-health should receive mainstream services where appropriate (Department of Health, 2011). This is consistent with the Equality Act (2010; Wadham, 2021) which puts a responsibility on public sector services to make "reasonable adjustments" to ensure mainstream provision is made accessible to groups with protected characteristics, including those with ID. Likewise, the Care Quality Commission (CQC) emphasises people's rights under the Equality Act (2010) to have reasonable adjustments, which requires English NHS Trusts to make reasonable adjustments to mainstream services to ensure the services are accessible to those with ID. Public sector bodies such as the NHS also have a duty to monitor their procedures to ensure their treatments for people with ID are accessible (Equality Act, 2010).

However, while the policy demands in England in this area are clear, there remains relatively little literature, and fewer models and outcomes, to inform how the provision of psychotherapy in mainstream mental health services can be reasonably adapted. The guidance for adaptations which may apply to people with ID has been primarily derived from clinical experience, rather than from existing outcome data (Dagnan, Taylor & Burke, 2023; Haddock

& Jones, 2006). This gap is significant as people with ID are likely to have a range of specific needs, arising from inherent intellectual impairment and a lack of personal independence that should be considered within psychological interventions. Furthermore, whilst CBT is an effective treatment for a broad range of mental health difficulties (Hofmann et al, 2012), and has been identified as a first line intervention for the treatment of various psychological and mood disorders in typically developing populations (e.g., NICE, 2011; 2013), the research which informs treatment guidelines for the general population typically does not include people with ID. Although therapeutic outcomes within ID populations have historically been under-researched, there has also been a long-held view within the psychiatric and psychological literature that mainstream psychotherapeutic interventions, such as CBT, may be less effective for people with ID, as the cognitive components of psychotherapy will be inaccessible due to intellectual impairments (Hassiots et al., 2011).

However, some evidence suggests that those with ID and affective disorders describe similar negatively biased thinking styles – including negative automatic thoughts, low selfesteem, and a generalised sense of hopelessness – to mainstream populations (Esbensen & Benson, 2005; Glenn, Bihm, & Lammers, 2003). Thus, it may be unsafe to assume that the underlying cognitive and affective processes associated with mood disorders in the general population are fundamentally different for people with ID. Furthermore, the assumptions that people with ID have insufficient intellectual capacity to engage meaningfully with talking therapies and lack the core cognitive skills required for CBT-based interventions, has been challenged by findings which suggests that many people with ID indeed possess the requisite, basic skills to successfully engage in CBT-based interventions (Dagnan, Mellor & Jefferson, 2009). For example, people with mild to moderate ID can establish links between thoughts and feelings, an important rationale underpinning CBT (Dagnan, Taylor & Burke, 2023) and have also demonstrated a capacity to acquire these skills (e.g., Bruce et al, 2010). Research

also suggests that CBT can be an effective intervention for several mood disorders, including anxiety, anger and depression, in people with ID (e.g., Vereenooghe & Langdon, 2013; NICE, 2016; Graser et al, 2022). Research has also examined the effectiveness of CBTbased treatments, within ID cohorts, to treat a broad range of presentations, including symptoms of psychosis (Barrowcliff, 2008), trauma (Stenfert Kroese et al., 2016), and physical health related issues (McManus et al, 2014). Interestingly, comparatively fewer studies have examined the effectiveness of CBT-based interventions for anxiety amongst people with ID. Although a systematic review conducted by Dagnan and colleagues (2018) concluded that the evidence broadly suggests CBT is an effective treatment for anxiety for those with ID, much of this evidence is derived from single case reports and case series, due to the current limited availability of larger-cohort studies. Thus, larger-scale research is needed to examine the psychological needs of people with ID and to increase our understanding of the adaptations required to improve interventions for this group (Hassiotis et al., 2011).

Process factors relevant to intellectual disability

Evidence that people with ID can benefit from CBT-based therapies needs to be balanced against the broad and inherent difficulties which arise from impaired general cognitive functioning. This naturally entails an impaired ability to process, retain and recall novel information, is likely to be associated with deficits in planning and independently engaging in goal-directed behaviour, and may contribute to difficulties with emotional and other self-regulation activities (Dagnan, Taylor and Burke, 2023). Standard therapy provision is thus likely to fall short if not sensitively adapted and delivered. Service adaptation is particularly challenging, and therefore of clinical interest, within mainstream services where the specialist populations generally constitute a small subset of the overall population served. Adaptation does not typically require new interventions to be designed *de novo*, but rather attempting to determine whether processes used in mainstream therapies are effective and then attempting to identify which aspects of these processes require adjustment (Dagnan, Jackson & Eastlake, 2018). For example, Jahoda et al.'s (2017) modified behavioural activation intervention for depression was developed from an existing behavioural activation intervention used in mainstream services (Lejuez, Hopko & Hopko, 2001). Dagnan et al., (2018) highlight two other studies (Hassiotis et al. 2013; Lindsay et al. 2015) which developed a CBT-based intervention for depression and anxiety from mainstream transdiagnostic treatment modalities (Clark et al., 2009). Such research is important in helping to determine whether there are specific aspects of psychotherapy which are associated with improved therapeutic outcomes for people with ID, and thus contribute to an informed and empirical rationale for service adaptation.

Types of adaptation

Adaptation potentially encompasses a range of factors, such as therapy *type*, the duration of interventions, or the number of interventions which occur during the total referral period. Such factors are derivable variables from IAPT data. As Green and colleagues (2015) discuss, the IAPT programme routinely collects client data which permits periodical analyses and evaluations of the delivery of IAPT. Demographic data, including age, ethnicity, biological sex and residential postcode is routinely collected. Information regarding process factors, or client interactions with the service, is also recorded, including treatment type/intensity, total sessions attended, referral duration, and whether discharged was planned or unplanned. Clinical outcomes are determined using the Patient Health Questionnaire-9 (PHQ-9) and Generalised Anxiety Disorder-7 (GAD-7) tools, administered before and after treatment. As Green and colleagues (2015) summarise, the values of PHQ-9 and GAD-7 at entry determine a client's 'caseness' (defined as PHQ-9 ≥ 10 and GAD-7 ≥ 8), or severity of

depression or anxiety. These measures are subsequently used to determine a threshold for recovery following treatment, defined as those that have a PHQ-9 <10 *and* GAD-7 <8.

Various factors have been associated with poorer treatment outcomes including higher levels of social deprivation (Richardson et al., 2015), clients being on psychotropic medication (Knapstad, Nordgreen & Smith, 2023), unplanned discharge (Riblet et al., 2022), comorbid long-term conditions (Seaton et al., 2022) and the absence of interpersonal relationships or connectedness (Holt-Lunstad et al., 2015; Pietromonaco & Collins, 2017). Higher scores on the Work and Social Adjustment Scale (WSAS) suggest higher levels of psychopathology (Mundt et al., 2002) with higher levels of psychopathology sometimes associated with poorer treatment outcomes for both depression (Saunders et al., 2019; Lorenzo-Luaces, 2017) and anxiety (Penninx et al., 2021). Factors associated with improved outcomes include being employed (Knapstad, Nordgreen & Smith, 2023; Verbist, Huey, & Bennett, 2022), reduced waiting times (Saunders et al., 2020) and a higher number of treatment sessions though, as has been noted elsewhere, the dose-response effect of treatment appears to be non-linear, with the optimal number of active treatments varying between different therapies (Melville et al., 2023). Likewise, though there is some evidence which suggests higher intensity treatments CBT-based are associated with improved treatment outcomes for clients with depression, there is likely to be considerable variance in this finding across treatment modalities and client demographics. Within IAPT, there is also an association between referral year and recovery, such treatment outcomes have improved over the past decade. For example, clients receiving treatment between 2019 and 2020 reportedly obtained better treatment outcomes than those receiving treatment between 2012 and 2013 (Dagnan et al., 2022).

Within the context of ID, the type of therapy has been suggested as important with recommendation for more behavioural and less cognitive interventions (e.g. Jahoda et al.,

2017). Stenfert Kroese and colleagues (2014) also suggested that when adapting CBT for clients with ID, it is necessary to consider that the ability of this population to generalize and sustain techniques learned during intervention may be impaired. A number of studies also emphasise the need for repetition of therapeutic techniques and materials and making information accessible (e.g. Hurly, 2007; Wright, 2013). Kellet et al. (2015) likewise identified a need for reducing the complexity of therapeutic techniques by reducing the quantity of written materials and presenting simplified formulations. The duration and frequency of therapeutic sessions have also been identified in the current literature as relevant to treatment outcome for people with ID. Prangnell and Green (2008) and Rose et al. (2008) also identify a need for shorter sessions. Taylor and colleagues (2005) identified the importance of delivering treatment at the rate of two sessions per week, with a minimum of one session per week to maintain therapeutic momentum and prevent drift. Additionally, McManus and colleagues (2013) also suggest using twice weekly, 40-minute sessions. Interestingly, each participant in Taylor and colleagues (2005) study received 18 sessions of therapy. Taken together, the extant literature suggests that both the frequency and total number of sessions may be associated with more positive outcomes and that the number of sessions needed to attain a certain level of change/improvement may be higher amongst ID populations.

It is noteworthy, however, that there is often inconsistency in the clinical literature with respect to the factors that predict mental health outcomes. As Tiemens and colleagues (2019) emphasise, "known" predictors of mental health outcomes, such as age, sex and baseline symptom severity do not always reliably predict mental health outcomes. Older age, for example, has been associated with poorer mental health outcomes (Fournier et al., 2009) however the association between age and outcomes was observed to be negligible in one study of outcomes in IAPT (Green et al., 2015). A systematic review of CBT treatments for panic disorders and agoraphobia likewise concluded age was not associated with mental health outcomes (Porter & Chambless, 2015). As Tiemens and colleagues (2019) highlight other studies which also report contradictory findings for sex, with one study suggesting being female is associated with improved mental health outcomes, while other studies observe no association between sex and outcomes (Fournier et al., 2009; Porter & Chambless, 2015). Interestingly, Tiemens and colleagues (2019) also note that while baseline symptom severity has been observed to be an important predictor of treatment outcomes for both depression and anxiety a large meta-analysis observed that baseline severity was not associated with treatment outcome for depression (Weitz et al., 2015). Within the context of ID, a recent study (Melville et al., 2023) interestingly observed that while higher anxiety was associated with poorer treatment outcomes, higher baseline depression symptoms were associated with better treatment outcomes. Likewise, though it seems intuitive to assume waiting times have a uniformly deleterious impact upon treatment outcomes, this association is not observed in all contexts, with extended waiting times sometimes having a neutral or, in one instance a marginally beneficial impact, upon treatment outcomes (van Dijk et al., 2023). It is thus hard to determine, on the basis of any particular study, which factors are reliable predictors of treatment outcomes, and aggregated findings across multiple studies may be necessary to reliably establish which factors predict mental health outcomes in general for people with ID.

Aims / Proposed Research Questions

Though research in the field of psychotherapy for people with ID remains nascent, preliminary findings suggests that people with an intellectual disability have poorer mental health outcomes following psychological intervention (Dagnan et al., 2022). The current study aims to identify which factors influence and determine psychotherapeutic outcomes for

people with ID, and whether these factors are the same or different from the factors compared to people without ID.

The current study initially sought to establish the extent to which the matched groups

were similar or dissimilar in individual and social characteristics. The first questions

addressed by the current study is thus:

RQ1: Are there group differences in key demographic and treatment variables before

and after matching, between ID and non-ID groups? Key demographic and treatment

variables are as follows:

- A. Gender
- B. Age at referral
- C. Baseline GAD-7
- D. Baseline PHQ-9
- E. Work and Social Adjustment Scale
- F. Wait to second treatment.
- G. Total number of treatment appointments.
- H. Referral duration
- I. Social deprivation score of referring GP practice.
- J. Psychotropic medication (Nationally defined)
- K. Planned/Unplanned discharge
- L. Referral Year
- M. High versus Low intensity therapy
- N. Employment status (Nationally defined)
- O. Long term relationship (Nationally defined)
- P. Long term conditions

Previous research suggests that people with ID experience less favourable mental

health outcomes than those without ID. Thus, the second research question was:

RQ2: Are there differences in the proportion of people with an ID diagnosis who

recover and those without an ID diagnosis who recover, in the unmatched and the matched

groups?

Lastly, the current study addressed the following question, which constitutes the

primary issue the study was designed to examine:

RQ3: Are there differences in the factors which predict treatment outcome/ recovery for the matched group of people with ID and the matched group of clients without ID? Specifically, do the demographic and treatment variables listed in RQ1 have the same association with recovery for both ID and non-ID matched groups?

Analysing data from IAPT services allows a fine-grained examination of potential inequities in health outcomes. Identifying the factors which impact upon outcomes for ID and non-ID populations is also an important pre-requisite in understanding the way mainstream psychotherapy may need to be adapted for people with ID. Though the current study is based on IAPT data, the factors measured by IAPT typically apply to all psychotherapy settings, and the current findings may therefore be generalizable to any psychotherapeutic services for people with ID.

Method

Design

The Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust IAPT service currently has over ten years of anonymised service user data including 81,216 unique referrals, of which three-hundred-and-twenty-six people were identified as on the learning disability register (0.4% of the total IAPT data set). It is likely that around 2.2% of the general population have an intellectual disability (Office for National Statistics, 2020). However, the GP registers in England typically do not identify more than 0.4-0.6% of this population (Shemtob et al, 2021). The Joint Strategic Needs Assessment (JSNA) for Cumbria in 2017 (Learning Disabilities Autism JSNA. December 2017) identified that the Cumbrian registers were identifying 0.5% of the total Cumbrian population as people with intellectual disabilities. Given that a small proportion of people on the GP registers will be people with severe and profound disabilities who would not be able to access IAPT, a prevalence of 0.4% in the IAPT data based on GP registers may be reasonably representative. The present study analysed the first available treatment for each person. This provides 81,216 people with at least one referral. Within IAPT, a referral can consist of an initial triaging assessment with no further therapeutic contact through to full engagement with up to 20+ treatment contacts before discharge. In the current study, only those with complete recovery data were analysed.

These data presented a challenge for analysis because the group of people with intellectual disabilities with complete recovery data was substantially smaller (n = 128) than the group with complete recovery data who do not have an intellectual disability (n = 41357). Subsequent comparisons between these two groups would thus be affected by the disparity in group sizes. Furthermore, attempts to identify associations between predictors and outcomes would be affected by any systematic core differences in the group characteristics that may be present between groups. It is plausible that groups of people with intellectual disabilities are systematically different, according to specific individual characteristics, such as age, or social/personal characteristics such as employment and marital status, compared to much larger groups of people who do not have intellectual disabilities. Matching was thus used as a solution to this problem (see the Planned Analysis section for more information about this process).

Participants

A cohort of 41357 people with complete recovery data was analysed. Of this initial cohort, the unmatched non-ID group comprised of 41229 people (M_{age} 41.52; SD_{age} 15.33; 63.7% male). The unmatched group of people with ID was N = 128 (M_{age} 31.29; SD_{age} 11.82: 55.5% male). Following the matching process, the matched group of clients without ID was N = 127 (M_{age} 31.15; SD_{age} 11.80; 55.1% male) while the matched cohort of people with ID was 127 (M_{age} 31.25; SD_{age} 11.86); 55.1% male).

Measures

The IAPT dataset has a number of codes for referral data (e.g., demographics, diagnostic category, referral source, waiting times, initial scores on GAD-7 PHQ-9, WSAS), process data (e.g., numbers of sessions, duration of engagement, type of intervention, leaving IAPT early and if referred to other services which services) and outcomes (e.g., GAD-7, PHQ-9, WSAS, IAPT defined categories 'recovery, clinically meaningful change, clinically meaningful recovery').

For those people in treatment, GAD-7, PHQ-9 and WSAS scores were available for every session. Taken together, this provided a set of variables where differences in outcomes between people who have ID could be considered in terms of a range of potential predictor variables. This allowed the factors associated with clinical outcomes for people with ID who received psychotherapy delivered by IAPT to be explored. Furthermore, access to a large sample of people who had also received a psychotherapeutic intervention in IAPT, but who did not disclose an ID, allowed consideration of whether there were factors which specifically predicted outcomes for people with ID.

Clinical characteristics, namely initial scoring on the GAD-7, PHQ-9 and the WSAS, all provided quantitative data on initial severity. The type of therapist the client saw, such as a CBT therapist or a psychological wellbeing practitioner, was also coded for, in terms of low intensity or high intensity. Process variables also included clinical outcomes, in terms of the GAD-7 and PHQ-9 adjustment scores, and codes for different classes of recovery. The key variables available for analysis within the IAPT data set are described below.

Outcome variable: Recovery. IAPT provides several related outcomes. The current study used the basic "recovery" metric. Within IAPT, a person is defined as "recovered" when initial scores on depression and/or a relevant specific anxiety disorder measure are above the clinical cut-off at start of treatment and *both* are below the clinical cut-off at the end of treatment (IAPT Manual, 2018).

Depressive symptoms: The *Patient Health Questionnaire* (PHQ-9; Kroenke et al., 2001) was developed with the aim of providing a questionnaire that combined brevity with "construct and criterion validity" (Ford et al., 2020; Kroenke et al., 2001, p. 612). The nine items on the PHQ-9 correspond to the nine DSM-IV diagnostic criteria for depression. The PHQ-9 asks clients to provide a score, using a four-point scale ranging from "not at all" to "most days," to indicate the frequency with which they have experienced certain depression symptoms in the preceding 2 weeks. Total scores range from 0-27, with depression severity categorized thus: 0-4 none, 5-9 mild, 10-14 moderate, 15-19 moderately severe, 20-27 severe. In IAPT services, depression is assessed using the PHQ-9 with a "caseness" threshold score of 10. "Caseness" refers to a level of symptoms likely to be sufficient for meeting diagnostic criteria for the measured disorder. The psychometric properties of the PHQ-9 were previously reported in large-scale study in the United States in a primary care setting (Kroenke et al., 2001). The PHQ-9 displayed good internal reliability ($\alpha = 0.89$) while test-retest reliability was also good, with a test-retest coefficient of 0.84. The psychometric properties of the PHQ-9 based on data from the Cumbrian population are described in Boothroyd et al (2018, 2019).

Anxiety symptoms: The 7-item Generalized Anxiety Disorders Scale (GAD-7; Spitzer et al., 2006) was developed as a screen for generalized anxiety disorder (GAD) in primary care settings. The seven items assess (1) feeling nervous, anxious, or on edge; (2) being able to stop or control worrying; (3) worrying too much about different things; (4) trouble relaxing; (5) being restless; (6) becoming easily annoyed or irritable; and (7) feeling afraid as if something awful might happen. The GAD-7 asks clients to provide a score, using a fourpoint scale ranging from "not at all" to "nearly every day." Total scores range from 0-21, with anxiety severity categorized thus: 0–4: minimal anxiety 5–9: mild anxiety 10–14: moderate anxiety 15–21: severe anxiety. In IAPT services, anxiety is assessed using the GAD-7 with a "caseness" threshold score of ≥ 8 . The GAD-7 has displayed strong psychometric properties with one large-scale study (Spitzer et al., 2006) reporting excellent internal reliability ($\alpha = 0.92$) and good test-retest reliability, with a test-retest coefficient of 0.83. The psychometric properties of the GAD-7 based on data from the Cumbrian population are described in Boothroyd et al (2018, 2019).

Functional impairment: The Work and Social Adjustment scale (WSAS; Mundt et al., 2002) comprises of 5 items (work, home management, social leisure, private leisure, and relationships), with each rated on 9-point Likert-type scale from 0 "not at all impaired" to 8 "very severely impaired" as a client-reported outcome. Total scores ranges from 0 to 40, with higher scores suggesting higher levels of disability. Scores above 20 indicate moderate, severe or worse impairment, though scores between 10 and 20 also represent significant functional impairment. Scores below 10 are considered subclinical (Mundt, Marks, Shear, & Greist., 2002). The WSAS has displayed good psychometric properties, with Mundt et al., (2002) reporting measures of internal consistency ranging from good ($\alpha = 0.70$) to excellent ($\alpha = 0.94$), with a test-retest correlation coefficient of 0.73. The psychometric properties of the WSAS when used in NHS Talking Therapies are described in Zahra et al (2014).

Long-term conditions. Known as Long-Term Physical Health Conditions (LTCs) in the NHS Data Model and Dictionary (<u>NHS Data Model and Dictionary: Long Term Physical</u> <u>Health Condition</u>), LTCs are described as health problems that require ongoing management over a period of years or decades. They are classified as conditions that cannot currently be cured but can be controlled with the use of medication and/or other therapies. This was available as a dichotomous variable identifying whether an LTC was present; the specific type of LTC was not available. In the present study, the presence of an LTC was coded as "1" and the absence of an LCT was coded as "0".

Relationship status: known as *Personal Marital Status* in the NHS Data Model and Dictionary. The client's relationship status was recorded in the current data-set. Responses of

married, long-term relationship and co-habiting were collapsed into a 'in relationship' code, and "Divorced", "Separated", "Single" were collapsed into a 'not in relationship' code (<u>NHS</u> <u>Data Model and Dictionary: Person Marital Status</u>). In the present study, it was coded as "1" if a client was in a relationship, while it was coded as "0" if the client was not in a relationship.

Employment status (known as Employment Status in the NHS Data Model and Dictionary): The client's employment status at the start of therapy was recorded. This was collapsed into a dichotomous variable, such that the single response 'employed' was coded as "1" and all other responses (including retired, in education less than 16 hours and not otherwise seeking work, unemployed), were coded a "0" (<u>NHS Data Model and Dictionary:</u> Employment Status).

Psychotropic medicine (known as Psychotropic Medication Usage Indication Code in the NHS Data Model and Dictionary). This was collapsed into a dichotomous variable, such that the response 'taking prescribed medication' was coded as "1" and 'prescribed but not taking' and 'not taking prescribed medication' were coded as "0".(<u>NHS Data Model and Dictionary: Psychotropic Medication Usage Indication Code</u>).

Reasons for leaving therapy (known as Discharge from Improving Access to Psychological Therapies Services Reason in the NHS Data Model and Dictionary). IAPT provides a number of codes for this variable. In the present study, the data were dichotomised with 'mutually agreed discharge' coded as "1" and all other reasons coded were judged to be a 'non-mutually agreed discharge' and coded as "0" (<u>NHS Data Model and</u> Dictionary: Discharge From Improving Access To Psychological Therapies Service Reason).

Days from first to second treatment was used as an indicator of waiting time and as a measure of 'intensity' of treatment. There are several variants of waiting measure in IAPT. However, the IAPT Therapies Manual (<u>IAPT Manual, 2018</u>) states: *services should (also)* guard against in-service pathway waits within a course of treatment. This means that there should not be an excessive wait between the first and second appointment for a particular therapy. If the therapy sessions are generally meant to be weekly or fortnightly, then the gap between the first and second session should be similar. This measure was chosen as it is both a more accurate measure of waiting time and potentially acts as a measure of the 'intensity' of treatment offered.

Referral Duration in days. This is the number of days from referral to discharge.

Total number of treatment sessions. IAPT records the total number of contacts and classifies the activities taking place in the session. Total number of contacts is available but in this analysis, it was decided to use the number of treatment sessions recorded for the referral

Therapy step. Data were available in several fields that indicate whether clients received therapy at Step 2 (Psychological Wellbeing Practitioners) or Step 3 (High intensity Therapists). This was evident in codes for the profession of the practitioner, the 'type' of therapy the client received, and as the initial step into which the client was entered. The latter field is used to identify whether clients were in low intensity (Step 2) or high intensity (Step 3) treatments.

Referring GP practice IMD deprivation score. Due to the anonymization of client data, client post-codes were not available. However, the Index of Multiple Deprivation (IMD) for an individual's referring GP practice was available in the current data-set, and was originally taken from the National General Practice Profiles pages

(https://fingertips.phe.org.uk/profile/general-practice). The IMD is a complex measure in which multiple components of deprivation are weighted with different strengths and compiled into a single score of deprivation. (A brief introduction to IMDs can be found at https://assets.publishing.service.gov.uk/media/5d8b399a40f0b609946034a4/IoD2019_Infographic.pdf). The core areas included are income, employment, education, health and crime,

barriers to housing and services, and living environment. Importantly, *lower* scores indicate a *higher* level of social deprivation. For example, a postcode with a score of 1000 is regarded as *less* deprived than an area with a score of 500.

Referral year. The data in this study cover a 10-year period. Significantly, national data shows systematic variation in recovery rates over this period, such that outcomes within IAPT have generally improved over time (e.g. Dagnan et al, 2022). Thus, the year of referral is considered as an important service variable.

Other demographic variables

Age in years. Age at time of referral; as data are anonymised, a client's date of birth was not available and age was available to the nearest whole year.

Gender; known as the *Gender Identity Code* in the *NHS the NHS Data Model and Dictionary.* This codes self-identified gender and includes codes other than Male and Female, although only these two codes were used by respondents in both the matched groups.

Data considerations: ethics handling, and governance

The current data were available in a format that could be directly read into SPSS and other statistical programs, though SPSS was used to derive the current results. The data used are fully anonymised and were initially obtained within the NHS and anonymised for the purpose of service improvement. National NHR/NES advice is that analysis of data of this type would not require ethical approval (<u>https://www.hra.nhs.uk/covid-19-research/guidance-using-patient-data/#how</u>) and are not generally considered under General Data Protection Regulation (GDPR).

The CNTW Foundation Trust considered how best to governance this type of data and suggested that the project should be registered formally as a service evaluation. This ensured a transparent governance structure in a context where standard ethical and HRA processes are not required and no other governance frameworks were required; although CNTW trust

recognised that this project is *not* a service evaluation. The IAPT records were/are fully anonymised and contain no identifiable information. The CNTW trust determined, as such, that a data sharing agreement between CNTW and UEA was not required. The CNTW R&D Department and IG leads confirmed on 01.12.22 that data sharing could take place for the purposes of analysis (project reference: SER-22-055). A key characteristic of the data which supported this decision is that the data were legally extracted and processed for the purpose of service evaluation in 2019; at which time the data were fully anonymised.

Throughout the current study, all data were shared securely between nhs.net or nhs.uk email accounts and kept on an encrypted NHS laptop for analysis. All data were stored on an NHS password-protected system and was handled in accordance with UEA institutional and research ethics policies. The data will remain on the NHS laptop for the duration of the project or until publication of any papers from the project. Faculty of Medicine and Health Sciences (FMH) ethical approval was sought on the basis of the current project utilising anonymised secondary dataset. Ethical approval was granted on 31 Jan 2023. The project was thus formally registered with the University of East Anglia.

Planned Analysis

To reduce systematic differences between ID and non-ID groups, two matched groups were created. The matched groups of people with ID and those without ID were compared on both the variables used in matching and those not used in matching to determine whether the matching has produced effectively equal groups. This was necessary as, in general, matching on specific factors means that there may still be other factors that systematically differ between groups (Pearce, 2016).

Matching was carried out using the SPSS case matching function. This algorithm uses 'fuzzy logic' to find best-fit cases within the defined parameters. The matching parameters were set *a priori* to avoid any sense of using matching as an exploratory analysis. From the data identified in the introduction, core demographic and clinical characteristics of the person (age, gender, baseline GAD-7 and baseline PHQ-9), a broad social factor (deprivation score for referring GP practice) and a reflection of the changing nature of NHS Talking Therapies over the course of the data period (year of referral), were used for matching. It quickly became evident that using the GP deprivation score would not allow matching, as this effectively required participants who matched on all other variables to also be registered with the same GP practice. Although there are around 50 practices in Cumbria (the exact number changes on an annual basis), some are very small due to the rurality of Cumbria and the inclusion of this variable led to loss of participants, such that the groups were only 50% of the possible total of 128. Several iterations of matching were completed in order to achieve the best balance of matching and sample size (similar to the approaches described by Stuart, 2010). An exact match on gender, +/- 1 point on age and referral year and +/- 2 point on baseline GAD-7 and PHQ-9 provided matched groups of 127 people with ID and 127 people without ID. The matching parameters were considered sufficiently close to proceed with these groups.

The present analysis involved unmatched group t-tests for continuous variables and chi-square with cross tabulations for dichotomous variables. Several authors identify that although data are case matched a "standard" (unconditional) analysis, may be more appropriate and may increase precision (Pearce, 2016).

Exploring the impact of predictor variables on outcomes, namely "recovery" as defined by IAPT, involved considering each variable separately. The initial analysis of the matched groups identified that some non-matched variables remained different between the groups. Specifically, groups remained significantly different on employment status, relationships status, and the presence of a long-term condition, such that those with ID were less likely to be employed and less likely to be in a long term relationship relative to matched

individuals without ID, yet likelier to have a long-term condition than matched individuals without ID. The analysis of the impact of predictor variables on outcomes was thus carried out as logistic regressions with recovery (as a dichotomous variable) regressed against possible predictor variables. This was carried out in two steps. First, the recovery variable was regressed onto the variables upon which the two groups differ. The second step added the variable of interest to determine whether statistically significant further variance was accounted for. Tables are presented below (Table 4) showing the significance of each step and the individual significance of each variable of interest.

Logistic regression makes some assumptions about the data being analysed (Stoltzfus, 2011; Field, 2017). Its basic requirements are that the dependent variable is dichotomous, that there are no significant outliers in the data (which primarily applies to any continuous independent variables), and that the data are independent (for example, that the data do not include repeated measures). In addition, logistic regression requires that there is no severe multi-collinearity in the data in each analysis (i.e. that variables are not very highly correlated with each other) and that there is a linear relationship between each continuous explanatory variable and the logit of the response variable (Stoltzfus, 2011; Field, 2017). The data used in the present analyses meet the requirement of a dichotomous dependent variable and the independence of data points. To check for significant outliers, the continuous independent variables in each analysis were converted to standardised scores and none had values outside of a range of +/- 3.0. To check for multi-collinearity the Variance Inflation Factor (VIF) was calculated for each analysis; a figure of above 10.00 would be considered to illustrate severe multi-collinearity. None of the independent variables in the analyses reported have VIF values above 1.5, with all in the range 1.0-1.5. To check the linear relationship between continuous variables and the logit of the dependent variable, the Box-Tidwell method was used (Tabachnick & Fidell, 2019; Field, 2017). Each continuous variable was subject to a log

transformation and the product of this transformation and the original variable was put into the logistic regression. None of these transformed variables had a significant relationship with the dependent variables indicating that the assumption of linearity with the logit of the dependent variable was not violated.

Results

Descriptive statistics for all groups – unmatched people without ID, matched people without ID and matched people with ID – across all continuous and dichotomous variables are listed in the appendices D & E respectively. Results of all *t-tests* for continuous variables and of all chi square and cross tabulations for dichotomous variables are also included. These data demonstrate the consistency of the current study's results, in that none of the significant variables in these data lose significance in the logistic analysis. Likewise, the logistic analysis did not identify any further variables as significant.

To address whether there are differences in the recovery variable between people with an ID diagnosis and those without an ID diagnosis, in both the unmatched and the matched groups, chi square tests and cross tabulations were performed. Table 1 shows the key comparison of outcomes for people with and without intellectual disabilities before and after matching. It is of particular importance to note that in the unmatched groups there is a significant difference in recovery rates ($\chi 2 = 7.03$; df = 1; p = 0.008). However, this reduced to a non-significant level ($\chi 2 = 0.02$; df = 1; p = 0.90) after matching, suggesting that matching equalised some of the key factors that may be influencing outcomes at an unmatched level.

To examine whether there are group differences in key demographic and treatment variables before and after matching, between ID and non-ID groups, independent sample ttest were performed across all continuous variables. To examine this question across all dichotomous variables, chi-square and cross tabulations were performed. Tables 2 and 3

show comparisons between the matched group of people with intellectual disabilities and the matched group of those without intellectual disabilities for continuous and dichotomous variables respectively on the remaining unmatched key variables. Table 2 shows the continuous variables and table 3 shows the dichotomous variables. The tables show while there are no significant differences in the continuous variables for matched groups of people with and without intellectual disability, there are significant differences in the matched groups on the dichotomous variables of employment ($\chi 2 = 41.066$, df = 1, p = <0.001, OR = 0.178), long-term relationship ($\chi 2 = 18.85$, df = 1, p = <0.001, OR = 0.317) and long-term condition ($\chi 2 = 12.87$, df = 1, p = <0.001, OR = 3.085), such that people with ID are less likely to be in employment or in long-term relationships and more likely to be registered as having a long-term condition.

The current study then sought to determine whether there are differences in the factors which predict treatment outcome/ recovery for people with ID versus those clients without ID. Specifically, the current study sought to determine whether demographic and treatment variables listed in RQ1 have the same association with recovery for both ID and non-ID groups. Logistic regressions were performed to ascertain the association of key variables with recovery status for the matched group with ID and the matched group without ID. The variable of recovery was regressed separately onto the dichotomous predictor variables age, gender, psychotropic medication, planned/unplanned discharge and high/low intensity therapy. The variable of recovery was also regressed separately onto the continuous variables of baseline GAD-7, baseline PHQ-9, WSAS, referral length, treatment count (total number of appointments), wait to second treatment and social deprivation score.

Each analysis is carried out in two steps, in each analysis the first step accounts for variance in employment, relationship status and long-term condition described above, as it was not possible to match the ID and non-ID groups according to these variables. The second
step shows the additional effect of each predictor being tested on the outcome variable of recovery. For people without ID, age, gender, psychotropic medication, high/low intensity therapy, baseline GAD-7, baseline PHQ-9, baseline WSAS, referral length, wait to second treatment and social deprivation score were not associated with recovery. The variable treatment count was associated with recovery ($\chi 2$ (6.120, n = 121), Wald = 5.780, *p* = .016, OR = 1.099, 95% CI [1.018 – 1.186]), such that a higher number of treatments was significantly associated with people meeting the IAPT threshold for recovery. Planned/unplanned discharge was also associated with recovery, ($\chi 2$ (32.232, n = 110), Wald = 24.192, *p* = <.001, OR = 0.83, 95% CI [.031 – .224]) such that people whose discharge was not agreed were statistically less likely to meet the IAPT threshold for recovery than those people whose discharge was planned.

For people with an intellectual disability, age, gender, psychotropic medication, high/low intensity therapy, baseline PHQ-9 scores, and baseline WSAS scores were not associated with recovery. As with the group without an intellectual disability the variable treatment count was associated with recovery ($\chi 2$ (6.845, n = 117), Wald = 6.113, *p* = .013, OR = 1.119, 95% CI [1.024 – 1.224]), such that a higher number of treatments was significantly associated with people meeting the IAPT threshold for recovery. Planned/unplanned discharge was also associated with recovery, ($\chi 2$ (32.232, n = 119), Wald = 24.192, *p* = <.001, OR = 0.83, 95% CI [.031 – .224]) such that people whose discharge was unplanned were statistically less likely to meet the IAPT threshold for recovery than those people whose discharge was planned. However, additional variables were found to be associated with recovery status in this group. Baseline GAD-7 score was associated with recovery, ($\chi 2$ (5.432, n = 119), Wald = 5.018, *p* = .025, OR = 1.095, 95% CI [1.011 – 1.186]), such that higher baseline GAD-7 scores were associated with a greater likelihood of recovery. p = .008, OR = .95, 95% CI [.915 – .987]), such that a shorter duration between first and second treatment was associated with a greater likelihood of recovery. Referral duration was associated with recovery ($\chi 2$ (5.529, n = 119), Wald = 5.224, p = .022, OR = 1.004, 95% CI [1.001 – 1.008]), such that a longer overall duration of referral was associated with a greater likelihood of recovery. Finally, the deprivation level of referring GP practise, as measured by the IMD score, was associated with recovery ($\chi 2$ (5.283, n = 119), Wald = 4.980, p = .026, OR = .939, 95% CI [.888 – .992]) such that people referred from practices with *lower* IMD scores (indicating a higher level of social deprivation) were less likely to recover.

Table 1: IAPT Recovery: recovery rates across unmatched ID and non-ID groups

| Group | | Not Recovered | Recovered | Total |
|-------------------|------------|---------------|-----------|-------|
| Non-ID | N (count) | 21580 | 19649 | 41229 |
| | Recovery % | 52.3 | 47.7 | 100 |
| LD | N (count) | 82 | 46 | 128 |
| | Recovery % | 64.1 | 35.9 | 100 |
| Chi-Squared Tests | | | | |
| | | Value | df | р |

7.03

41357

1

** *denotes p* < 0.01)

χ2

Ν

IAPT Recovery: recovery rates across matched ID and non-ID groups

| Group | | Not Recovered | Recovered | Total |
|--------|------------|---------------|-----------|-------|
| Non-ID | N (count) | 82 | 45 | 127 |
| | Recovery % | 64.6 | 35.4 | 100 |
| LD | N (count) | 81 | 46 | 127 |
| | Recovery % | 63.8 | 36.2 | 100 |

Chi-Squared Tests

0.008**

| | Value | df | р |
|----|-------|----|-------|
| χ2 | 0.017 | 1 | 0.896 |
| Ν | 254 | | |

** *denotes p* < 0.01)

| | Unmatche | ed group | | | | | | | Matched g | group | | | | | | |
|--|------------------|----------|--------------------|-------|-------|--------|--------------------|-----------------------|------------------|--------|------------------|-------|-------|--------|--------------------|----------------|
| Variable | People wi | th ID | People wi | thout | | | | | People wi | th ID | People wi | thout | | | | |
| | Mean (n) | SD | Mean (n) | SD | t | df | Sig. (2 tailed) | Effect size (d) | Mean (n) | SD | Mean (n) | SD | t | df | Sig. (2 tailed) | Effect size |
| Age | 31.29 (128) | 11.82 | 41.52 (41229) | 15.33 | 9.77 | 128.33 | < 0.001 | 0.67 | 31.25 (127) | 11.80 | 31.14 (127) | 11.86 | -0.07 | 252 | 0.94 | -0.01 |
| Baseline GAD-7 | 13.43 (128) | 5.39 | 13.06 (41229) | 5.20 | -0.81 | 41355 | 0.42 | -0.07 | 13.54 (127) | 5.27 | 13.46 (127) | 5.25 | -0.11 | 252 | 0.95 | -0.01 |
| Baseline PHQ-9 | 14.48 (128) | 6.43 | 14.36 (41229) | 6.20 | -0.22 | 41355 | 0.83 | -0.02 | 14.47 (127) | 6.44 | 14.47 (127) | 6.33 | -0.07 | 252 | 0.98 | -0.01 |
| First WSAS | 16.17 (125) | 9.93 | 17.82 (40475) | 9.92 | 1.96 | 40598 | 0.05 | 0.17 | 16.27 (124) | 9.90 | 18.44 (123) | 9.83 | 1.73 | 245 | 0.086 | 0.22 |
| Days referral to 2 nd treatment session | 23.47 (109) | 20.24 | 22.56 (36513) | 19.75 | -0.48 | 36620 | 0.631 | -0.05 | 23.56 (108) | 20.32 | 20.18 (96) | 16.32 | -1.30 | 202 | 0.195 | -0.18 |
| Treatment appointments | 5.67 (126) | 4.66 | 6.01 (40443) | 4.59 | .845 | 40567 | 0.40 | 0.08 | 5.70 (125) | 4.66 | 6.14 (121) | 5.133 | .710 | 240.01 | .478 | 0.09 |
| Referral duration | 169.45 (128) | 105.32 | 161.22 (41229) | 96.16 | 965 | 41355 | 0.33 | -0.09 | 170.06 (127) | 105.51 | 176.58 (127) | 131 | .437 | 252 | .663 | 0.05 |
| GP deprivation score | 23.20 (128) | 7.97 | 22.06 (37595) | 7.66 | -1.68 | 37721 | .09 | -0.15 | 23.27 (127) | 7.96 | 22.93 (113) | 7.30 | .347 | 238 | .729 | -0.04 |
| Referral year | 2013.97 (128) | 3.08 | 2014.35 (41229) | 3.05 | 1.41 | 41355 | 0.159 | 0.12 | 2013.97 (127) | 3.09 | 2013.37 (127) | 2.88 | -1.60 | 252 | .112 | -0.20 |

Table 2: comparison of continuous variables for unmatched people with and without intellectual disabilities and matched groups with and without intellectual disabilities.

| Table 3: comparisons dichotomous variables for unmatched people with and without intellectual disabilities and matched groups with and without intellectual | |
|---|--|
| disabilities. | |

| | Unmatched groups | | | | | | | Matched Groups | | | | | | | | |
|---|------------------------|---------------------|-------------------------|------------------|----------|----|---------|-----------------------------|---------------|---------------|-------------------|----------------|----------|----|---------|-------------------------|
| Variable | People wi within Pe | People w (% with | vithout ID in people | | | | | People w | vith ID | People w | People without ID | | | | | |
| | Yes (%) | No (%) | Yes (%) | No (%) | χ^2 | df | sig | OR (95% CI) | Yes (%) | No (%) | Yes (%) | No (%) | χ^2 | df | sig | OR (95% CI) |
| Gender (Yes = Female; No = Male) | 71 (55.5%) | 57 (44.5%) | 26263 (63.7%) | 14959 (36.3%) | 3.78 | 1 | 0.053 | 0.71 (0.50 -1.00) | 70 (55.1%) | 57 (44.9%) | 70 (55.1%) | 57 (44.9%) | 0.00 | 1 | 1.00 | 1.00 (.610 – 1.64) |
| Treatment Step (Yes = PWP; No = HIT) | 34 (26.6%) | 94 (73.4%) | 6637 (16.1%) | 34553 (83.9%) | 10.291 | 1 | 0.001 | 1.883 (1.271 – 2.79) | 34 (26.8%) | 93 (73.2%) | 24 (18.9%) | 103 (81.1%) | 2.234 | 1 | 0.135 | 1.569 (.867 - 2.839) |
| Psychotropic medication (Yes/No) | 58 (46.8%) | 66 (53.2%) | 19051 (46.9%) | 21547 (53.1%) | 0.01 | 1 | 0.973 | 0.99 (0.70 - 1.42) | 57 (46.3%) | 66 (53.7%) | 61 (48.8%) | (51.2%) | 0.15 | 1 | 0.698 | .906 (.55 – 1.492) |
| Planned discharge (Yes/No) | 80 (62.5%) | 48 (37.5%) | 27178 (65.9%) | 14051 (34.1%) | .001 | 1 | 0.973 | 0.862 (0.602 – 1.233) | 79 (62.2%) | 48 (37.8%) | 68 (53.5%) | 59 (46.5%) | 1.954 | 1 | 0.162 | 1.428 (.866 - 2.355) |
| Employed (Yes/No) | 32 (25.6%) | 93 (74.4%) | 27023 (65.8%) | 14024 (34.2%) | 89.54 | 1 | <0.001 | 0.179 (0.119 – 0.267) | 32 (25.8%) | 92 (74.2%) | 84 (66.1%) | 43 (33.9%) | 41.066 | 1 | <0.001 | 0.178 (.103 307) |
| Long-term relationship (Yes/No) | 35 (28.5%) | 88 (71.5%) | 23628 (57.8%) | 17245 (42.2%) | 43.29 | 1 | < 0.001 | 0.29 (0.20 - 0.43) | 35 (28.7%) | 87 (71.3%) | 71 (55.9%) | 56 (44.1%) | 18.85 | 1 | < 0.001 | 0.317 (.188 537) |
| Long-term condition (Yes/No) | 41 (32%) | 87 (68%) | 8564 (20.8%) | 32665 (79.2%) | 9.82 | 1 | 0.002 | 1.79 (1.24 - 2.61) | 41 (32.3%) | 86 (67.7%) | 17 (13.7%) | 110 (86.6%) | 12.87 | 1 | <0.001 | 3.085 (1.64 - 5.803) |

| | | | | | j·j· | |) | - P ~, = = = | | | | |
|--------------------|------|-------|-------|-------|----------------|-------|-----------------|---------------------|-------|-------|----------------|-------|
| | | | | Model | 1 (n=119) | | Model 2 (n=119) | | | | | |
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 653 | 0.428 | 2.329 | 0.521 | (0.225, 1.204) | 0.127 | 677 | 0.441 | 2.363 | 0.508 | (0.214, 1.205) | 0.124 |
| Relationship (Yes) | .137 | 0.433 | 0.10 | 1.147 | (0.491, 2.679) | 0.751 | .153 | 0.438 | 0.122 | 1.165 | (0.494, 2.746) | 0.727 |
| LTC (yes) | 307 | 0.413 | 0.552 | 0.736 | (0.328, 1.653) | 0.458 | 315 | 0.415 | 0.577 | 0.73 | (0.447, 0.730) | 0.447 |
| Gender | | | | | | | 095 | 0.403 | 0.056 | 0.909 | (0.813, 0.909) | 0.813 |

IAPT Recovery: Employment, Relationships, LTC and Gender

IAPT Recovery: Employment, Relationships, LTC and Age at Referral

| | | | | Model | | | Model 2 (n= 119) | | | | | |
|--------------------|------|-------|-------|-------|----------------|-------|------------------|-------|-------|-------|----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 653 | 0.428 | 2.329 | 0.521 | (0.225, 1.204) | 0.127 | 680 | 0.430 | 2.497 | 0.507 | (0.218, 1.178) | 0.114 |
| Relationship (Yes) | .137 | 0.433 | 0.10 | 1.147 | (0.491, 2.679) | 0.751 | .113 | 0.435 | 0.068 | 1.120 | (0.478, 2.625) | 0.794 |
| LTC (yes) | 307 | 0.413 | 0.552 | 0.736 | (0.328, 1.653) | 0.458 | 014 | 0.416 | 0.651 | 0.715 | (0.317, 1.615) | 0.420 |
| Age at Referral | | | | | | | .489 | 0.018 | 0.613 | 0.986 | (0.952, 1.021) | 0.433 |

IAPT Recovery: Employment, Relationships, LTC and First GAD-7

| | | | | Model | 1 (n=119) | | | | Model 2 (n= 119)Wald OR 95% CI OR Sig. | | | | | |
|--------------------|------|-------|-------|-------|----------------|-------|------|-------|--|-------|----------------|-------|--|--|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. | | |
| | | | | | | | | | | | | | | |
| Employed (Yes) | 653 | 0.428 | 2.329 | 0.521 | (0.225, 1.204) | 0.127 | 680 | 0.440 | 2.381 | 0.507 | (0.214, 1.202) | 0.123 | | |
| Relationship (Yes) | .137 | 0.433 | 0.10 | 1.147 | (0.491, 2.679) | 0.751 | .185 | 0.443 | 0.175 | 1.204 | (0.506, 2.866) | 0.675 | | |
| LTC (yes) | 307 | 0.413 | 0.552 | 0.736 | (0.328, 1.653) | 0.458 | 226 | 0.423 | 0.286 | 0.798 | (0.348, 1.827) | 0.593 | | |
| FirstGAD-7 | | | | | | | .091 | 0.041 | 5.018 | 1.095 | (0.011, 1.186) | 0.025 | | |

| | | | | Model | | | | | Mode | el 2 (n= 119) | | |
|--------------------|------|-------|-------|-------|----------------|-------|------|-------|-------|---------------|----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 653 | 0.428 | 2.329 | 0.521 | (0.225, 1.204) | 0.127 | 656 | 0.429 | 2.339 | 0.519 | (0.224, 1.203) | 0.126 |
| Relationship (Yes) | .137 | 0.433 | 0.10 | 1.147 | (0.491, 2.679) | 0.751 | .141 | 0.435 | 0.106 | 1.152 | (0.491, 2.700) | 0.745 |
| LTC (yes) | 307 | 0.413 | 0.552 | 0.736 | (0.328, 1.653) | 0.458 | 306 | 0.413 | 0.549 | 0.736 | (0.328, 1.654) | 0.459 |
| First PHQ-9 | | | | | | | .003 | 0.031 | 0.010 | 1.003 | (0.944, 1.066) | 0.919 |

IAPT Recovery: Employment, Relationships, LTC and First PHQ-9

IAPT Recovery: Employment, Relationships, LTC and First WSAS

| | | | | Model | 1 (n=116) | | | Model 2 (n=116) | | | | | |
|--------------------|------|-------|-------|-------|----------------|-------|------|-----------------|-------|-------|----------------|-------|--|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. | |
| | | | | | | | | | | | | | |
| Employed (Yes) | 658 | 0.430 | 2.338 | 0.518 | (0.223, 1.204) | 0.126 | 632 | 0.432 | 2.136 | 0.532 | (0.228, 1.240) | 0.532 | |
| Relationship (Yes) | .138 | 0.435 | 0.101 | 1.148 | (0.490, 2.693) | 0.750 | .126 | 0.436 | 0.083 | 1.134 | (0.482, 2.667) | 1.134 | |
| LTC (yes) | 373 | 0.418 | 0.797 | 0.689 | (0.304, 1.562) | 0.372 | 357 | 0.419 | 0.726 | 0.700 | (0.308, 1.591) | 0.700 | |
| FirstWSAS | | | | | | | .019 | 0.021 | 0.862 | 0.981 | (0.942, 1.022) | 0.981 | |

IAPT Recovery: Employment, Relationships, LTC and Wait to Second Treatment

| | | | | Model | 1 (n=103) | - | | | Model 2 (n= 103) | | | | | | |
|--------------------|------|-------|-------|-------|----------------|-------|------|-------|------------------|-------|----------------|-------|--|--|--|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. | | | |
| | | | | | | | | | | | | | | | |
| Employed (Yes) | 513 | 0.443 | 1.342 | 0.599 | (0.251, 1.426) | 0.247 | 531 | 0.470 | 2.136 | 0.588 | (0.234, 1.478) | 0.259 | | | |
| Relationship (Yes) | .138 | 0.449 | 0.095 | 1.148 | (0.476, 2.768) | 0.758 | .185 | 0.473 | 0.083 | 1.203 | (0.476, 3.039) | 0.696 | | | |
| LTC (yes) | 331 | 0.434 | 0.580 | 0.718 | (0.307, 1.683) | 0.446 | 007 | 0.455 | 0.726 | 0.993 | (0.408, 2.422) | 0.989 | | | |
| WaittoSecondTrt | | | | | | | 051 | 0.019 | 0.862 | 0.95 | (0.915, 0.987) | 0.008 | | | |

| | | | | Model 1 | (n=117) | | | | | Mode | el 2 (n = 117) | |
|---------------------|------|-------|-------|---------|----------------|-------|-----|-------|-------|-------|----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| Employed (Yes) | 614 | 0.429 | 2.053 | 0.541 | (0.234, 1.254) | 0.152 | 549 | 0.441 | 1.549 | 0.578 | (0.243, 1.371) | 0.213 |
| Relationship (Yes) | .101 | 0.436 | 0.054 | 1.106 | (0.471, 2.599) | 0.816 | 058 | 0.450 | 0.017 | 0.943 | (0.390, 2.280) | 0.897 |
| LTC (yes) | 328 | 0.415 | 0.624 | 0.720 | (0.319, 1.626) | 0.430 | 236 | 0.431 | 0.300 | 0.790 | (0.339, 1.838) | 0.584 |
| Total_Trt_Appointme | | | | | | | 113 | 0.046 | 6.113 | 1.119 | (1.024, 1.224) | 0.013 |
| nts | | | | | | | | | | | | |

IAPT Recovery: Employment, Relationships, LTC and Days to Total Treatment Appointments

IAPT Recovery: Employment, Relationships, LTC and Referral Duration

| | | | | Model | 1 (n=119) | | | | | Mode | el 2 (n= 119) | |
|--------------------|------|-------|-------|-------|----------------|-------|------|-------|-------|-------|----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 653 | 0.428 | 2.329 | 0.521 | (0.225, 1.204) | 0.127 | 539 | 0.438 | 1.827 | 0.553 | (0.234, 1.306) | 0.176 |
| Relationship (Yes) | .137 | 0.433 | 0.10 | 1.147 | (0.491, 2.679) | 0.751 | .155 | 0.446 | 0.120 | 1.167 | (0.487, 2.800) | 0.729 |
| LTC (yes) | 307 | 0.413 | 0.552 | 0.736 | (0.328, 1.653) | 0.458 | 329 | 0.442 | 0.607 | .720 | (0.314, 1.647) | 0.436 |
| Referral Duration | | | | | | | .004 | 0.002 | 5.224 | 1.004 | (1.001, 1.008) | 0.022 |

IAPT Recovery: Employment, Relationships, LTC and Social Deprivation Score

| | | | | Model | 1 (n=119) | | | | | Mode | el 2 (n=119) | |
|------------------------|------|-------|-------|-------|----------------|-------|-----|-------|-------|-------|----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 653 | 0.428 | 2.329 | 0.521 | (0.225, 1.204) | 0.127 | 258 | 0.464 | 0.308 | 0.773 | (0.311, 1.920) | 0.579 |
| Relationship (Yes) | .137 | 0.433 | 0.10 | 1.147 | (0.491, 2.679) | 0.751 | 114 | 0.454 | 0.063 | 0.892 | (0.366, 2.174) | 0.802 |
| LTC (yes) | 307 | 0.413 | 0.552 | 0.736 | (0.328, 1.653) | 0.458 | 325 | 0.422 | 0.592 | 0.723 | (0.316, 1.653) | 0.442 |
| SocialDeprivationScore | | | | | | | 063 | 0.028 | 4.980 | 0.939 | (0.888, .992) | 0.026 |

| | | | | Model | 1 (n=117) | | | | | Mode | el 2 (n=117) | |
|--------------------|------|-------|-------|-------|----------------|-------|------|-------|-------|-------|----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 563 | 0.434 | 1.684 | 0.570 | (0.243, 1.333) | 0.194 | 566 | 0.435 | 1.689 | 0.568 | (0.242, 1.333) | 0.194 |
| Relationship (Yes) | .113 | 0.434 | 0.067 | 1.119 | (0.478, 2.618) | 0.795 | .103 | 0.435 | 0.056 | 1.109 | (0.473, 2.599) | 0.813 |
| LTC (yes) | 315 | 0.414 | 0.581 | 0.730 | (0.324, 1.641) | 0.446 | 333 | 0.415 | 0.642 | 0.717 | (0.318, 1.618) | 0.423 |
| Psychotropic_Meds | | | | | | | 323 | 0.395 | 0.671 | 0.724 | (0.334, 1.569) | 0.413 |

IAPT Recovery: Employment, Relationships, LTC and Psychotropic Medication

IAPT Recovery: Employment, Relationships, LTC and Planned/Unplanned Discharge

| | | | | Model | 1 (n=119) | | | | | Mode | l 2 (n= 119) | |
|-----------------------|------|-------|-------|-------|----------------|-------|-------|-------|--------|--------|----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 653 | 0.428 | 2.329 | 0.521 | (0.225, 1.204) | 0.127 | 623 | 0.484 | 1.655 | 0.536 | (0.208, 1.386) | 0.198 |
| Relationship (Yes) | .137 | 0.433 | 0.10 | 1.147 | (0.491, 2.679) | 0.751 | 284 | 0.503 | 0.319 | 0.753 | (0.281, 2.018) | 0.572 |
| LTC (yes) | 307 | 0.413 | 0.552 | 0.736 | (0.328, 1.653) | 0.458 | 230 | 0.464 | 0.244 | 0.795 | (0.320, 1.975) | 0.621 |
| Plan/unplan_Discharge | | | | | | | 2.539 | 0.589 | 18.611 | 12.673 | (3.998, 40.17) | <.001 |

Model 1 (n=119) Model 2 (n=119) В SE Wald Wald Variables OR В SE 95% CI OR Sig. OR 95% CI OR Sig. -.653 0.428 2.329 0.521 0.104 -.706 0.494 (0.211, 1.155)Employed (Yes) (0.225, 1.204)0.127 .434 2.647 Relationship (Yes) .137 0.433 0.10 1.147 (0.491, 2.679)0.751 .076 .438 .030 1.079 (0.457, 2.544)0.863 LTC (yes) -.307 0.413 0.552 0.736 (0.328, 1.653) -.375 .420 .796 0.687 (0.301, 1.567)0.372 0.458 -.076 .066 1.324 0.927 (0.815, 1.055)0.250 ReferralYear

IAPT Recovery: Employment, Relationships, LTC and Referral Year

| | | | | U I U | | 1 / | | 0 | | 0 10 | |
|--------------------------|------|-------|---------|----------------|-------|------|-------|-------|-------|----------------|-------|
| | | | Model 1 | (n=119) | | | | | Mode | el 2 (n= 119) | |
| Variables | В | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | |
| Employed (Yes) | 653 | 2.329 | 0.521 | (0.225, 1.204) | 0.127 | 800 | 0.445 | 3.227 | 0.449 | (0.188, 1.075) | 0.072 |
| Relationship (Yes) | .137 | 0.10 | 1.147 | (0.491, 2.679) | 0.751 | .151 | 0.437 | 0.729 | 1.164 | (0.495, 2.738) | 0.729 |
| LTC (yes) | 307 | 0.552 | 0.736 | (0.328, 1.653) | 0.458 | 369 | 0.419 | 0.773 | 0.692 | (0.304, 1.573) | 0.379 |
| High/low_thrpy_Intensity | | | | | | 651 | 0.445 | 2.138 | 0.522 | (0.304, 1.573) | 0.144 |

IAPT Recovery: Employment, Relationships, LTC and High/Low intensity therapy

Logistic regression tables for matched non-ID Group

IAPT Recovery: Employment, Relationships, LTC and Gender

| | | | | Model | 1 (n=127) | | | | | Mode | el 2 (n= 127) | |
|--------------------|------|-------|-------|-------|----------------|-------|------|-------|-------|-------|----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 551 | 0.424 | 1.689 | 0.576 | (0.251, 1.323) | 0.194 | 564 | 0.426 | 1.753 | 0.569 | (0.247, 1.311) | 0.186 |
| Relationship (Yes) | 495 | 0.390 | 1.618 | 0.609 | (0.284, 1.307) | 0.203 | 491 | 0.390 | 1.584 | 0.612 | (0.285, 1.314) | 0.208 |
| LTC (yes) | .943 | 0.676 | 1.946 | 2.569 | (0.682, 9.672) | 0.163 | .898 | 0.687 | 1.709 | 2.454 | (0.639, 9.431) | 0.191 |
| Gender Code | | | | | | | .150 | 0.388 | 0.150 | 1.162 | (0.543, 2.486) | 0.698 |

IAPT Recovery: Employment, Relationships, LTC and Age at Registration

| | | | | Model | 1 (n=127) | | | | | Mode | el 2 (n= 127) | |
|--------------------|------|-------|-------|-------|----------------|-------|------|-------|-------|-------|----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 551 | 0.424 | 1.689 | 0.576 | (0.251, 1.323) | 0.194 | 513 | 0.428 | 1.437 | 0.599 | (0.259, 1.385) | 0.231 |
| Relationship (Yes) | 495 | 0.390 | 1.618 | 0.609 | (0.284, 1.307) | 0.203 | 427 | 0.396 | 1.164 | 0.652 | (0.300, 1.417) | 0.281 |
| LTC (yes) | .943 | 0.676 | 1.946 | 2.569 | (0.682, 9.672) | 0.163 | .924 | 0.678 | 1.859 | 2.520 | (0.667, 9.518) | 0.173 |
| AgeAtReg | | | | | | | .018 | 0.016 | 1.205 | 1.018 | (0.986, 1.051) | 0.272 |

| | | | | Model | 1 (n=127) | | | | | Mode | el 2 (n= 127) | |
|--------------------|------|-------|-------|-------|----------------|-------|------|-------|-------|-------|-----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | _ | | | | | | - |
| Employed (Yes) | 551 | 0.424 | 1.689 | 0.576 | (0.251, 1.323) | 0.194 | 486 | 0.432 | 1.270 | 0.615 | (0.264, 1.433) | 0.260 |
| Relationship (Yes) | 495 | 0.390 | 1.618 | 0.609 | (0.284, 1.307) | 0.203 | 524 | 0.392 | 1.784 | 0.592 | (0.274, 1.278) | 0.182 |
| LTC (yes) | .943 | 0.676 | 1.946 | 2.569 | (0.682, 9.672) | 0.163 | .975 | 0.680 | 2.057 | 2.651 | (0.699, 10.044) | 0.152 |
| FIRST_GAD-7 | | | | | | | 031 | 0.038 | 0.691 | 0.969 | (0.901, 1.043) | 0.406 |

IAPT Recovery: Employment, Relationships, LTC and FirstGAD-7

IAPT Recovery: Employment, Relationships, LTC and First PHQ-9

| | | | | Model | 1 (n=127) | | | | | Mode | el 2 (n= 127) | |
|--------------------|------|-------|-------|-------|----------------|-------|------|-------|-------|-------|-----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 551 | 0.424 | 1.689 | 0.576 | (0.251, 1.323) | 0.194 | 480 | 0.430 | 1.248 | 0.619 | (0.266, 1.437) | 0.264 |
| Relationship (Yes) | 495 | 0.390 | 1.618 | 0.609 | (0.284, 1.307) | 0.203 | 498 | 0.391 | 1.617 | 0.608 | (0.282, 1.309) | 0.204 |
| LTC (yes) | .943 | 0.676 | 1.946 | 2.569 | (0.682, 9.672) | 0.163 | .978 | 0.682 | 2.055 | 2.658 | (0.698, 10.114) | 0.152 |
| FIRST_PHQ-9 | | | | | | | 034 | 0.031 | 1.216 | 0.966 | (0.909, 1.027) | 0.270 |

IAPT Recovery: Employment, Relationships, LTC and First WSAS

| | | | | Model | 1 (n=123) | | | | | Mode | el 2 (n= 123) | |
|--------------------|-------|-------|-------|-------|----------------|-------|-------|-------|-------|-------|-----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 460 | 0.430 | 1.144 | 0.631 | (0.272, 1.466) | 0.285 | 407 | 0.436 | 0.871 | 0.665 | (0.283, 1.565) | 0.351 |
| Relationship (Yes) | 445 | 0.393 | 1.281 | 0.641 | (0.297, 1.385) | 0.285 | 433 | 0.397 | 1.193 | 0.648 | (0.298, 1.411) | 0.275 |
| LTC (yes) | 1.009 | 0.677 | 2.224 | 2.743 | (0.728, 10.33) | 0.136 | 1.044 | 0.681 | 2.351 | 2.842 | (0.748, 10.802) | 0.125 |
| FIRST_WSAS | | | | | | | 032 | 0.020 | 2.419 | 0.969 | (0.931, 1.008) | 0.120 |

| | | | | Model | 1 (n=96) | | | | | Мо | odel 2 (n=96) | |
|--------------------|-------|-------|-------|-------|----------------|-------|-------|-------|-------|-------|-----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 661 | 0.479 | 1.910 | 0.516 | (0.202, 1.319) | 0.167 | 631 | 0.484 | 1.701 | 0.532 | (0.206, 1.373) | 0.192 |
| Relationship (Yes) | 706 | 0.437 | 2.613 | 0.493 | (0.209, 1.162) | 0.106 | 721 | 0.439 | 2.699 | 0.486 | (0.206, 1.149) | 0.100 |
| LTC (yes) | 1.150 | 0.710 | 2.626 | 3.158 | (0.786, 12.69) | 0.105 | 1.157 | 0.710 | 2.654 | 3.182 | (0.791, 12.806) | 0.103 |
| WaittoSecondTrt | | | | | | | 006 | 0.014 | 0.211 | 0.994 | (0.968, 1.020) | 0.646 |

IAPT Recovery: Employment, Relationships, LTC and Wait to Second Treatment

IAPT Recovery: Employment, Relationships, LTC and Total Treatment Appointments

| | | | | Model | | Model 2 (n= 121) | | | | | | | |
|------------------------|------|-------|-------|-------|----------------|------------------|------|-------|-------|-------|----------------|-------|--|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. | |
| | | | | | | | | | | | | | |
| Employed (Yes) | 535 | 0.432 | 1.531 | 0.586 | (0.251, 1.366) | 0.216 | 480 | 0.442 | 1.183 | 0.619 | (0.260, 1.470) | 0.277 | |
| Relationship (Yes) | 487 | 0.397 | 1.509 | 0.614 | (0.282, 1.337) | 0.219 | 552 | 0.410 | 1.814 | 0.576 | (0.258, 1.286) | 0.178 | |
| LTC (yes) | .948 | 0.684 | 1.921 | 2.582 | (0.675, 9.869) | 0.166 | .956 | 0.689 | 1.921 | 2.600 | (0.673, 10.04) | 0.166 | |
| Total_Trt_Appointments | | | | | | | .094 | 0.039 | 5.780 | 1.099 | (1.018, 1.186) | 0.016 | |

IAPT Recovery: Employment, Relationships, LTC and Referral Duration

| | | | | Model | Model 2 (n= 127) | | | | | | | |
|--------------------|------|-------|-------|-------|------------------|-------|------|-------|-------|-------|----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 551 | 0.424 | 1.689 | 0.576 | (0.251, 1.323) | 0.194 | 560 | 0.425 | 1.733 | 0.571 | (0.248, 1.315) | 0.188 |
| Relationship (Yes) | 495 | 0.390 | 1.618 | 0.609 | (0.284, 1.307) | 0.203 | 542 | 0.397 | 1.862 | 0.582 | (0.267, 1.267) | 0.172 |
| LTC (yes) | .943 | 0.676 | 1.946 | 2.569 | (0.682, 9.672) | 0.163 | .934 | 0.677 | 1.902 | 2.545 | (0.675, 9.599) | 0.168 |
| Referral Duration | | | | | | | .001 | 0.001 | 0.467 | 1.001 | (0.998, 1.004) | 0.494 |

| | | | Model 1 | Model 2 (n=113) | | | | | | | | |
|------------------------|-------|-------|---------|-----------------|----------------|-------|-------|-------|-------|-------|-----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 688 | 0.437 | 2.476 | 0.503 | (0.213, 1.184) | 0.116 | 712 | 0.440 | 2.615 | 0.491 | (0.207, 1.163) | 0.106 |
| Relationship (Yes) | 595 | 0.408 | 2.125 | 0.552 | (0.248, 1.228) | 0.145 | 619 | 0.411 | 2.265 | 0.538 | (0.240, 1.206) | 0.132 |
| LTC (yes) | 1.148 | 0.682 | 2.835 | .3151 | (0.828, 11.98) | 0.092 | 1.219 | 0.692 | 3.103 | 3.385 | (0.872, 13.142) | 0.078 |
| SocialDeprivationScore | | | | | | | .016 | 0.029 | 0.327 | 1.016 | (0.961, 1.075) | 0.568 |

IAPT Recovery: Employment, Relationships, LTC and Social Deprivation Score

IAPT Recovery: Employment, Relationships, LTC and Psychotropic Medication

| | | | | Model | 1 (n=125) | Model 2 (n= 125) | | | | | | |
|--------------------|------|-------|-------|-------|----------------|------------------|-------|-------|-------|-------|----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 535 | 0.427 | 1.571 | 0.586 | (0.254, 1.352) | 0.210 | 541 | 0.428 | 1.599 | 0.582 | (0.252, 1.346) | 0.206 |
| Relationship (Yes) | 586 | 0.396 | 2.195 | 0.557 | (0.256, 1.208) | 0.138 | 583 | 0.396 | 2.168 | 0.558 | (0.257, 1.213) | 0.141 |
| LTC (yes) | .940 | 0.678 | 1.921 | 2.559 | (0.678, 9.665) | 0.166 | .946 | 0.678 | 1.946 | 2.575 | (0.682, 9.729) | 0.163 |
| Psychoytopic_Meds | | | | | | | -1.27 | 0.386 | 0.107 | 0.881 | (0.413, 1.878) | 0.743 |

IAPT Recovery: Employment, Relationships, LTC and Planned/Unplanned Discharge

| | | | | Model 1 | | | | Model 2 (n= 127) | | | | |
|--------------------|------|-------|-------|---------|------------------|-------|--------|------------------|--------|-------|-----------------|---------|
| Variables | В | SE | Wald | OR | 95% CI <i>OR</i> | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| Employed (Yes) | 551 | 0.424 | 1.689 | 0.576 | (0.251, 1.323) | 0.194 | 411 | 0.426 | 0.722 | 0.663 | (0.256, 1.712) | 0.396 |
| Relationship (Yes) | 495 | 0.390 | 1.618 | 0.609 | (0.284, 1.307) | 0.203 | 562 | 0.390 | 1.567 | 0.570 | (0.236, 1.374) | 0.211 |
| LTC (yes) | .943 | 0.676 | 1.946 | 2.569 | (0.682, 9.672) | 0.163 | 1.032 | 0.687 | 1.951 | 2.808 | (0.660, 11.953) | 0.162 |
| Plan/unplan_Disch | | | | | | | -2.488 | 0.388 | 24.192 | 0.083 | (0.031, .224) | < 0.001 |
| arge | | | | | | | | | | | | |

| | | | | Model 1 | | | | | Model 2 (n= 12) | 7) | | |
|--------------------|------|-------|-------|---------|----------------|-------|------|-------|-----------------|-------|----------------|-------|
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | | | | | | | |
| Employed (Yes) | 551 | 0.424 | 1.689 | 0.576 | (0.251, 1.323) | 0.194 | 582 | 0.428 | 1.851 | 0.559 | (0.242, 1.292) | 0.174 |
| Relationship (Yes) | 495 | 0.390 | 1.618 | 0.609 | (0.284, 1.307) | 0.203 | 488 | 0.391 | 1.558 | 0.614 | (0.285, 1.321) | 0.212 |
| LTC (yes) | .943 | 0.676 | 1.946 | 2.569 | (0.682, 9.672) | 0.163 | .939 | 0.678 | 1.922 | 2.559 | (0.678, 9.659) | 0.166 |
| ReferralYear | | | | | | | .073 | 0.066 | 1.204 | 1.075 | (0.944, 1.225) | 0.273 |

IAPT Recovery: Employment, Relationships, LTC and Referral Year

IAPT Recovery: Employment, Relationships, LTC and High/Low intensity therapy

| | | | | | | t I | i ș | | 1 / | 0 | Ŭ | 10 |
|-------------------------|------|-------|-------|-------|----------------|------------------|------|-------|-------|-------|----------------|-------|
| | | | | Model | | Model 2 (n= 127) | | | | | | |
| Variables | В | SE | Wald | OR | 95% CI OR | Sig. | В | SE | Wald | OR | 95% CI OR | Sig. |
| | | | | | | 0 | | | | | | 0 |
| Employed (Yes) | 551 | 0.424 | 1.689 | 0.576 | (0.251, 1.323) | 0.194 | 554 | 0.425 | 1.700 | 0.575 | (0.250, 1.321) | 0.192 |
| Relationship (Yes) | 495 | 0.390 | 1.618 | 0.609 | (0.284, 1.307) | 0.203 | 494 | 0.390 | 1.610 | 0.610 | (0.284, 1.309) | 0.204 |
| LTC (yes) | .943 | 0.676 | 1.946 | 2.569 | (0.682, 9.672) | 0.163 | .936 | 0.679 | 1.899 | 2.550 | (0.674, 9.652) | 0.168 |
| High/low_thrpy_Intensit | ty | | | | | | .060 | 0.494 | 0.015 | 0.941 | (0.358, 2.479) | 0.903 |

Discussion

The current study examined whether the factors which predict recovery for people with intellectual disabilities accessing IAPT services are equivalent or different to those factors which predict recovery for people from the mainstream population. It was found that the factors which predict recovery for people from the general population also predict recovery for people with ID. However, there are also factors which only predict recovery for people with ID. The discussion will first review the factors which predict outcomes for both people with and without ID and then consider the factors which, in the context of the present data, uniquely predict outcomes for the group of people with ID.

It is necessary to recall that the initial group of people with ID who had recovery data was substantially smaller compared the non-ID group who had recovery data. Case-control matching was undertaken to ensure subsequent comparison between groups were not affected by the disparity in group sizes and to ensure associations between predictor and outcome variables were not affected by systematic core differences in the group characteristics. Comparisons were also carried out between unmatched groups. A key finding from the unmatched comparisons (table 1 & table 2) was that, across 10 years data, people with ID were substantially less likely to recover following therapy than clients from the mainstream population. Specifically, 35.9% of participants with ID, recovered, compared with 47.7% of people who recovered from the mainstream population. This finding is broadly consistent with national data; a report in 2012 that analysed data on the first 1 000 000 people referred to the service nationally observed recovery rates of 45% (Green et al., 2015), while people with ID within IAPT experience relatively poorer clinical outcomes (Dagnan, Rodhouse, Thwaites & Hatton, 2022). However, the current analysis may further develop understanding of differential mental health outcomes in ID and mainstream populations. Results suggested that when groups are matched, according to the core individual characteristics of age, gender,

and baseline anxiety and depression, which are well-established predictors of mental health outcomes, those with ID and without ID experience almost equivalent mental health outcomes, with 36.2% of people with ID recorded as having recovered, compared with 35.4% of the mainstream population recorded as having recovered. This finding tentatively raises the possibility that the differences in mental health outcomes experienced by ID and mainstream populations are, at least partly, driven by characteristics which are more prevalent for people with ID, but which are nonetheless present across both groups, rather than being driven by intrinsic and defining qualities of ID.

A higher number of treatment appointments was associated with recovery both for people with and without ID. This finding appears broadly consistent with previous research; one recent systematic review noted that the number of sessions received was a positive predictor of recovery, while participants who had not initially reached recovery experienced more favourable mental health outcomes when further sessions were offered (Amati, Banks, Greenfield & Green, 2018). The current study found those people with ID who recovered received 7.48 sessions, while matched non-ID clients who recovered received 7.64 sessions. Those people with ID who did not recover received 4.66 session while people without ID who did not recover received 5.25 sessions. These findings should also be understood within the context of the well-established dose-effect models of psychotherapy. Though the current study did not measure the relative contribution of each therapy session to recovery, prior recovery models demonstrate that the relationship between number of sessions and recovery is non-linear, with most improvement occurring during the initial stage of treatment (Howard, Kopta, Krause & Orlinsky, 1986). In particular, Rubel, Lutz & Schulte (2015) observed that the largest variation within therapy occurs during the first six sessions. In later phases, for example in sessions 7-12 and 13-18, clients were observed to experience smaller improvement, or no observable improvement at all. Therefore, those people who did not

recover may not necessarily have benefitted simply due to receiving additional sessions, although it is unclear whether additional sessions result in positive changes being more durable following therapy. In the current study, those who did not recover may have experienced little improvement during initial sessions, a well-established predictor of poorer outcomes (Rubel, Lutz & Schulte, 2015), resulting in lower therapy engagement and therapyinterfering behaviours, such as inconsistent attendance. However, as Melville and colleagues (2023) emphasise, attending all sessions is particularly important in manualised therapy schedules as "treatments are time limited and have a clear beginning, middle and end with unique elements of the treatment being introduced in each phase" (p.998). The current finding thus appear to speak to the importance of therapy completeness for all patients.

Consistent with this finding, unplanned discharge was negatively associated with recovery for both ID and non-ID groups. This aligns with previous studies which suggest that prematurely terminating therapy is associated with poorer clinical outcomes (Cahill et al. 2003; Delgadillo et al. 2014). This finding is consistent across a variety of treatment modalities, contexts and client populations (Barrett et al. 2008), and appears intuitive as prematurely terminating therapy means a treatment schedule has, by definition, not been adhered to and thus effective therapy is less likely to have been delivered. Other recent findings from IAPT services (Saxon, Firth, Barkham, 2017) similarly suggest that people who completed therapeutic interventions were significantly more likely to recover than those who did not, with only 12 % of clients who prematurely left therapy classified as having "recovered" compared with 60 % for people who completed therapy. These findings again emphasise the importance of therapy completeness for all clients. Discontinuing therapy in the absence of agreement between patient and client is likely to be a proxy for a range of process issues which impact upon the quality of the therapeutic relationship and the client's engagement with the therapeutic process. For instance, Bordin's model (1979) of the

therapeutic alliance emphasises that optimal therapy outcomes are best achieved when the tasks and goals of therapy are collaboratively agreed by client and therapist and a positive interpersonal bond is established. Leaving therapy prematurely may imply a lack of agreement on goals and tasks, also possibly a breakdown or failure to establish an interpersonal bond.

The current study also identifies additional factors which predict recovery only for people with ID. Referral duration was observed to predict recovery only for people with ID. Prior findings with respect to referral duration are equivocal, with some studies suggesting that both the number of sessions and referral duration are associated with positive treatment outcomes both in IAPT (Green et al., 2015) and other clinical settings (Cuijpers et al., 2013; Erekson et al., 2015). However, Saunders and colleagues (2020) observed that increasing the referral duration (number of weeks in treatment) was negatively predictive of positive treatment outcomes when number of sessions was held constant. Therefore, referral duration may only be associated with recovery if it is closely associated with number of treatment sessions and may not be independently predictive of recovery. Indeed, referral duration may be negatively predictive of outcomes if session frequency is inconsistent and prolonged periods occur between sessions. A meta-analysis by Cuijpers and colleagues (2013) observed a robust association between the number of sessions per week and the treatment effect size amongst people receiving psychotherapy for depression, whereas the total number of sessions and the overall duration of the therapy were not predictive of recovery. However, increasing the frequency of the sessions from one-per-week to two-per-week increased the efficacy of treatment, with findings suggesting a medium effect size (d = .45). In explaining the findings, referral duration was highly correlated with treatment count. However, in this study, although treatment count predicted recovery in both groups, referral duration only predicted recovery for people with ID. The measure of treatment contacts in this study is specific to treatment

activity and there may be other contacts (assessment and review) which do not contribute to the number of treatment sessions, and it is possible that these are more valued by people with intellectual disability. It is also plausible that merely being open to a service provides a sense of expectation of treatment, which may ameliorate some of the distressing cognitions associated with mental ill-health such as loneliness and hopelessness. This rationale is consistent with at least one previous study which observed a modest reduction in depressive symptoms in 512 mainstream patients who were waiting for inpatient psychotherapy, a finding which was attributed to the client's expectation that they would soon receive treatment (Jennissen et al., 2021). In the current study, people with ID were also significantly less likely to be in an intimate relationship and significantly more likely to be unemployed than matched non-ID individuals. Though the effects of employment and relationship status on recovery were controlled for in present analysis, methodologically this is not isomorphic with controlling for the effects of *loneliness*, which is a multidimensional construct. Unemployment and an absence of intimate relationships are undoubtedly potential signifiers of loneliness. Both these factors are associated with the scope and quality of one's social networks, opportunities for meaningful community participation and engagement, and opportunities for friendships and interpersonal connectedness (Gilmore & Cuskelly, 2014). Lower rates of employment and intimate relationships suggests people with ID may have been vulnerable to social isolation more broadly and its concomitant deleterious effects. An ongoing referral may have provided some basic sense of connection, a sense which is highly important for physical and psychological health (Holt-Lunstad et al., 2015), and which is often absent from the lives of people with ID.

In the current study, wait to second treatment was a significant predictor of recovery for people with ID, such that a reduced wait between first and second treatment was predictive of recovery. It is well-established that excessive waiting time in general, resulting

in untreated ill-health, can have a deleterious impact across a variety of health domains, including mental health, and impede a person's ability to benefit from treatment (Reichert & Jacobs., 2018; van Dijk et al., 2023). Days from first to second treatment is more nuanced and nationally defined statistic used in IAPT, serving as a proxy for therapy intensity and continuity. The frequency of therapeutic sessions is recognised as being associated with treatment outcomes for people with ID. Taylor (2005), for instance, identified the importance of delivering treatment at the rate of two sessions per week. Previous findings also suggest a greater intensity of therapy for people with ID may be important. McManus (2014), for example, suggests using twice weekly, 40-minute sessions. Prior studies have also emphasised the need for reducing the complexity of therapeutic techniques and the quantity of written materials (Kellet et al., 2015), repetition of therapeutic techniques and materials for people with ID (Hurly, 2007; Wright, 2013). Although such studies do not explicitly endorse an increased number or frequency of therapeutic contacts, an increased number of sessions and an increased frequency of therapeutic contacts naturally increases the possibility that techniques and materials can be repeated to clients, retained and recalled. This seems particularly important for people with ID.

Deprivation for referring GP practice was only a significant predictor of recovery for people with ID. Though it was not possible to construct matched groups according to IMD score, differences in IMD scores between the matched ID and non-ID groups were not statistically significant. There is a well-established relationship between socioeconomic deprivation and physical ill-health across the lifespan, increased lifetime prevalence of adverse mental-health outcomes and a greater likelihood of all-cause mortality (Kivimäki et al., 2020). The mechanisms underlying this relationship are undeniably complex and social deprivation measures are ultimately a proxy for multidimensional phenomena. The IMD, for example, comprises of material economic realities such as household income and levels of

employment, access to – and quality of – education and healthcare, crime, barriers to housing and services, and the living environment. A range of risk factors are also more prevalent among communities characterised by higher degrees of social deprivation, including lower levels of perceived autonomy with respect to one's health, risk-seeking behaviours such excessive alcohol consumption and substance misuse, and lower levels of health-promoting behaviours such as exercise. Though IMD scores capture community-level, rather than capturing individual level, deprivation, lower scores indicate an individual is likelier to encounter various sources of strain in their community, which are social, economic, psychological and physical in nature. The finding that IMD scores specifically predict recovery for people with ID may be explained by additional factors which often characterise the lives of people with ID, such as loneliness and isolation. This vulnerability appears due to three reciprocally influencing factors; social attitudes and expectations; opportunities and experiences; and skill deficits associated with ID (Gilmore & Cuskelly, 2014). ID also remains a stigmatizing characteristic (Scior, Potts & Furnham, 2013) and the contexts in which individuals with intellectual disability live, learn, and work continue to be characterised by reduced opportunities for social engagement and overt social rejection (Gilmore & Cuskelly, 2014). Difficulties with establishing and maintaining friendships may be impacted by their devalued status as well as difficulties in behaving in ways which are in accordance with peer expectations and social norms. The social networks of those with ID may also be restricted to others with intellectual disabilities, precluding important modelling opportunities (Gilmore & Cuskelly, 2014). The degree to which individuals are interpersonally interconnected (Holt-Lunstad, 2015) and embedded in communities have a powerful impact on physical health and psychological wellbeing (Emerson et al., 2021). People with ID often live isolated lives and feel excluded from their local communities (Power & Bartlett, 2018; Hall & Bates, 2019). Significantly, the presence of social and

interpersonal relationships has a well-established moderating effect on negative life events (Brown & Harris, 1978). The absence of strong interpersonal relationships may thus be best construed as a form of social and interpersonal privation, as those who are lonely and isolated are less able to benefit from the specific functions served by social connections. Interpersonal relationships can be a font of important resources which enable adaptive responses to stress, such being a source of practical help, emotional support and providing both parties with a sense of wider connectedness. A higher level of social deprivation is likelier to be more impactful upon those people who have a reduced access to such interpersonal resources. It is also well established that people with ID are at increased risk for both violent and sexual victimisation. In communities characterised by an increased incidence of crime, people with ID are thus at significantly greater risk of being victimised, which will undoubtedly have a deleterious impact upon mental health outcomes (Fogden et al., 2016).

The current study also finds that that higher GAD-7 scores, indicating a higher baseline anxiety, is predictive of recovery for people with ID. This finding should be treated with caution. Firstly, it is unclear whether there is any precedent for this finding in the extant literature. One prior study of IAPT data observed a not entirely dissimilar trend to the one observed in the current study, with higher GAD-7 scores being positively associated with *reliable improvement* rather than *recovery*. However, this finding appears more amenable to explanation as those people with a higher baseline anxiety essentially had greater scope for *reliable improvement* than those people with lower baseline anxiety, irrespective of whether or not they meet the threshold for recovery (Saunders et al., 2020). With respect to recovery, research suggests an opposite relationship, at least amongst mainstream demographics, with higher anxiety associated with less favourable mental health outcomes (Melville et al., 2023). The current findings thus appear anomalous and hard to explain, though it is noteworthy that Melville and colleagues (2023) observed a somewhat analogous finding, with higher baseline depressions scores associated with improved mental health outcomes. Though it is possible that higher baseline scores in depression or anxiety mean there is greater scope for improvement, it is unclear why this would not also apply to people without ID. It is possible that people with ID reporting a higher baseline anxiety were regarded as having more complex presentations, or as representing a higher level of risk, due to the additional vulnerabilities that ID entail. Such people may therefore have been prioritised for treatment, subsequently experiencing shorter waiting times, or offered a greater number of sessions. This would suggest that service process issues, rather than the intrinsic qualities of anxiety, account for the association between higher GAD-7 scores and recovery, though this rationale is purely speculative. However, it is not clear why this logic would not also apply to higher baseline depression scores, which may be associated with even greater risk than anxiety. Furthermore, although it is plausible that people with higher anxiety may also have been more motivated to attend sessions, it is not immediately clear why this would not also apply to people from mainstream populations. The current ID sample was also relatively modest in size (127) and the current findings would need to be replicated multiple times across larger samples before the current findings could be regarded as something other than anomalous.

Limitations

The current study has several limitations. Firstly, though the finding that recovery rates between ID and non-ID groups are almost equivalent once groups are matched according to a small number of variables is novel, this conclusion needs to be tested in a larger sample. Indeed, though the current study had a sample of total sample of 254 (127 people with ID), logistic regressions for the ID group were invariably based on smaller samples, ranging from 103 – 119, due to some data points being absent on specific variables. Likewise, in the non-ID group, one regression was run on a sample of 96. The need to test the current observations in a larger dataset is thus self-evident. Secondly, the IAPT data were

anonymised, and client-level geographical data was inaccessible. The GP postcode-linked method of determining a person's IMD score was judged to be a pragmatic approach which does not require client-level data. However, this method assumes that the deprivation score associated with the immediate locality in which the practice resides is a valid proxy for the socioeconomic deprivation experienced by individual members of the practice population. Though a previous examination of this method acknowledges that GP-linked postcode scores provide a useful proxy deprivation in the absence of client-level data, client-level data is nonetheless considered the gold standard for measuring deprivation (Strong, Maheswaran, Pearson & Fryers, 2007).

Another limitation of the current study is that the psychometric properties of the measures used by IAPT/NHS Talking Therapies, such as the GAD-7, PHQ-9, have been primarily established in mainstream populations. The GAD-7 and PHQ-9 are particularly important for monitoring outcomes within IAPT services as the nationally defined recovery variable is a composite score of these measures. More research is needed to understand the psychometric properties of the GAD-7 and PHQ-9 for people with ID, to ensure that these measures can accurately differentiate between those clients with ID who have recovered or not recovered, according to nationally defined standards. Indeed, a prior review (Hermans, van der Pas & Evenhuis, 2011) suggests the Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID) is arguably the most reliable self-report instrument for anxiety for people with ID, with strong internal consistency reported in this client group (a = 0.96). The Glasgow Depression Scale for people with a Learning Disability (GDS-LD) has also previously been identified as a reliable means of measuring depression for adults with ID, demonstrating a good test-retest reliability (r=0.97) and internal consistency (Cronbach's alpha=0.90) (Cuthill, Espie & Cooper, 2003). Further research is also needed to determine the psychometric properties of other measures, such as the WSAS, for people with ID to ensure

that such measures can be reliably used as potential predictors of recovery for people with ID who access IAPT/NHS Talking Therapies.

Another limitation of the current study is that it relies upon data from one IAPT service and it is conceivable there are regional factors specific to Cumbria, or to the history of the Cumbrian service, which systematically influence the results and limit the generalisability of the current findings. For example, Cumbria is more ethnically homogenous than other regions in the UK (Hayes et al., 2023). Though it is not immediately clear why this should limit generalizability, the homogeneity of Cumbria is not representative of the UK as a whole. IAPT is a psychotherapy model implemented nationally according to a standardized manual and there are likely to be more similarities than differences between IAPT services across England. This mitigates against the likelihood of regional differences contributing the systematic and significant differences in mental health outcomes. Nonetheless, future research is needed to determine whether the factors associated with recovery for people with ID in the current study are reliably associated with recovery for this demographic across other IAPT services and treatment modalities.

Finally, the concept of "matching" within a context characterised by being labelled as 'a person with an intellectual disability' warrants consideration. By definition, the contribution of ID to mental health outcomes can only be understood in relative terms yet both ID and mainstream populations are typically heterogeneous. The contribution of ID to mental health outcomes will inevitably vary according to the factors upon which matching occurs and the degree to which this produces similar or dissimilar groups. Opting for a higher number of matched criteria risks creating highly similar groups which obscure differences between ID and mainstream populations while restricting the matching criteria risks confounding the contribution of ID by failing to control for factors which systematically impact upon mental health outcomes for one particular group. It therefore appears difficult to

determine, in a principled way, how to capture the *intrinsic contribution* of ID to mental health outcomes, and to identify the factors which are intrinsically associated with outcomes for people with ID, relative to the mainstream population.

Finally, the current study has used a data linkage approach to identifying people with ID. The use of known diagnoses GP coding will under-identify people with potential diagnoses by a factor of 3. In addition, the diagnostic process inevitably excludes people who are on the border of the diagnosis but who may benefit from similar adaptations. It is difficult to estimate the numbers of people who may benefit from such adaptations, however, in the case of people with ID it makes little sense to suggest that an adaptation is required for someone with an IQ score of 70 or below, but not for someone with an IQ score slightly above 70. Thus this paper is focused on a specific group of people with ID who have had cause to be identified through contact with specialist or primary care services.

Clinical implications

Though there is a need to understand the underlying mechanisms between predictor variables and recovery, there are pragmatic considerations which self-evidently need to be considered, when considering how services can be adapted to better meet the needs of people with ID. Though increasing the number of therapeutic contacts may support recovery for people with ID, this also requires greater resources. Interestingly, the current findings may suggest how existing resources can be used more efficiently. For example, ensuring continuity of sessions appears to support recovery for people with ID, yet does not necessarily require additional resources. Continuity between sessions may be particularly important for people with ID, as an irregular timetable or increased waiting times between sessions may make it more difficult for people to form a stable therapeutic relationship. An irregular timetable and increased waiting times between sessions may also make it more difficult for people with intellectual impairments to meaningfully process, assimilate, retain

and utilise the task-related content delivered within therapy sessions. Furthermore, in highlighting the negative association between recovery and unplanned discharge, the current findings highlight the importance of the therapeutic relationship. Ensuring agreement on goals and tasks, developing a strong interpersonal bond, and prioritising relationship maintenance and repair, may be particularly important for people with ID. This finding suggests therapists should hold in mind the importance of therapeutic relationship and devote attentional resources to its development and maintenance if sources of strain in the relationship are identified, which again does not necessarily require additional economic resources, but a re-focussing of attentional resources.

The current study also identifies that people with ID with lower IMD scores are more vulnerable to poorer mental health outcomes. It is plausible – though beyond the scope of the current study – that allocating greater resources to those patients with ID with lower IMD scores may be more cost effective in the long-term, if fewer re-referrals are subsequently made, though at this moment this rationale is entirely speculative.

The differences in factors that predict outcomes for people with ID emphasises the importance of working with services to adapt their processes and training for IAPT therapists. Training and supports for IAPT in working with people with ID have been described in national best practice documents (Dagnan et al, 2015) and specific training outcomes have been initially reported (Dagnan et al, 2018). Further work to develop pathways and training supports is required and the data from this study can be used to build an empirical basis which informs this type of work. For example, as already identified, the need for regular and frequent sessions and the need to keep clients in therapy until there is a mutually agreed end-point might be emphasised.

Future research

Though the current study has not examined differences between unmatched groups, the data shows differences between unmatched groups exist. Further exploration of why the presenting ID population is different from the mainstream differences on core variables such as age and gender may be important. For example, although differences between baseline GAD-7 and PHQ-9 scores were not significant between unmatched ID and non-ID groups, differences between gender and age were statistically significant. Of clients with ID accessing IAPT 44.5% were male (44.5%) while 36.3% of those without ID were male and amongst unmatched individuals, those with ID accessing IAPT were also a decade younger (average age: 31.29 years) than those without ID (average age: 41.52 years). More research is needed to clarify why these demographic differences exist between ID and non-ID groups being referred to IAPT as both gender (women have better outcomes) and age (younger people do better) are known to impact outcomes and these data suggest important questions about why younger people with intellectual disabilities are not referred to IAPT at the same proportional rate as those without intellectual disabilities.

In the current study, the contribution of referral duration to recovery was unclear, though its contribution may be party explicable by its correlation with total treatment count. Previous research about the specific contribution of referral duration to recovery has resulted in inconsistent findings. Future research is needed to determine whether remaining open to services for a longer duration makes any specific contribution to recovery for people with ID, or whether its effect is largely explained by its correlation with treatment count. Research has also established that active treatment has a non-linear, dose response association with recovery. Though this naturally implies an upper limit, beyond which further active treatment is minimally associated with recovery, it is unclear what the optimal number of therapeutic sessions is for people with ID, and whether this number is similar or dissimilar to mainstream populations. It is possible that people with ID may respond more to the interpersonal aspects

of therapy, rather than its technical content and thus sessions that are not counted as therapy might have a bigger impact for this group.

Summary

In summary, the current study has contributed to the nascent literature on the factors which predict mental health recovery for people with ID accessing psychotherapy. Firstly, the current study identified that total number of sessions and disagreement on discharge are factors which predict recovery for all people. These factors appear to be interrelated and attest to the importance of a positive therapeutic relationship and completeness within psychotherapy. Broadly speaking, these findings also contribute to the growing recognition that people with ID benefit from accessing mainstream therapy provision. The current findings further suggest there are additional factors - therapy duration, wait to second treatment and social deprivation score - which impact on the treatment outcomes of those with ID compared to mainstream populations. The extant literature suggests that people with ID are more likely to be exposed to increased sources of strain, particularly those sources associated with social isolation. Factors such as social deprivation and waiting times may therefore be particularly impactful for people already experienced increased sources of strain, and who have less access to interpersonal resources which support recovery. The finding that higher GAD-7 score predict recovery for people with ID appears somewhat anomalous in the context of previous research.

To the knowledge of the authors, this is the first study to explicitly investigate whether the factors which predict recovery for people with ID accessing IAPT services are equivalent or different to those which predict recovery for people from the mainstream population. The present findings suggest there are specific factors associated with recovery for people with ID. This represents an important contribution to the nascent evidence base concerning therapeutic processes and outcomes for people with ID. Developing this evidence

base is essential to ensure that decisions about therapeutic adaptations for people with ID are empirically grounded. Although the current findings are based on data from IAPT services in Cumbria, all the factors which could have potentially contributed to treatment outcomes are generically applicable to all forms of psychotherapy, suggesting that the current findings may be generalizable to psychotherapeutic services beyond IAPT. Furthermore, although the current sample size of 254, composed of two matched groups of 127, is modest within the context of studies which examine national data, within the context of people with ID accessing psychotherapy there are few existing studies which have utilised equivalent sample sizes.

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Concluding Chapter

Discussion and critical evaluation

Word count: 2607

Discussion and critical evaluation

The current thesis comprised of two studies. The first study, using a qualitative metasynthesis methodology, explored whether Bordin's model (1979) of the therapeutic alliance describes how people with ID experience the therapeutic alliance. The second study explored whether the factors which are associated with recovery for people with accessing IAPT services are equivalent or dissimilar to those associated with recovery for people without ID. The qualitative meta-synthesis highlighted how clients with ID placed particular emphasis on interpersonal processes during psychotherapy. Humans may not merely have a desire for interpersonal connectedness. Rather, the need for connectedness may constitute a basic human need which reflects a central intrinsicality of human nature (Baumeister & Tice, 1990; Holt-Lunstad et al., 2015). While this desire and need may be a human universal, people with ID may place greater emphasis on interpersonal aspects of therapy relative to mainstream clients, due to their reduced access to supportive interpersonal relationships and the reduced opportunities for meaningful social engagement. It seems plausible, nonetheless, that the underlying processes which affect alliance formation for people with ID may be similar to those which affect alliance formation for mainstream populations, and that a strong affective bond is, in part, an emergent property of a shared focus on tasks and goals relevant to the client's wellbeing and psychological development. With respect to adaptation, the therapeutic relationship for clients with ID may require therapists to assume a pro-active role within the client's support network to a greater degree than is typical for mainstream clients. However, it may be premature to suggest that therapists specifically focus on investing additional resources in building therapeutic relationships, with a potential trade-off whereby tasks and goals receive less attention. Rather, it seems appropriate that therapists be mindful that the relationship is likely, from the client's perspective, to be an important feature – and outcome - of engagement in psychotherapy.

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The empirical paper observed that a higher number of therapy sessions was positively associated with recovery for all clients and that disagreements on discharge were negatively associated with recovery for all clients. For clients with ID, a greater level social deprivation was also negatively associated with recovery, while a higher baseline GAD-7, a short number of days to second treatment and a longer referral duration were positively associated with recovery. Unplanned discharge is likely to be a proxy for a range of process issues and the negative association between recovery and unplanned discharge underscores the importance of agreement between therapist and client. This rationale also may attest to the importance of the therapeutic alliance, and that agreement on goals and tasks, a strong interpersonal bond, and relationship maintenance and repair, are closely associated with therapeutic outcomes for all people. This finding suggests therapists should hold in mind the importance of therapeutic relationship and attend to its development and maintenance, which does not necessarily require additional economic resources. Shorter wait times between treatments suggests that continuity between sessions may be particularly important for people with ID. The positive relationship between referral duration and recovery for people with ID may possibly suggest that being open to a service provides a sense of expectation of treatment, which may ameliorate some of the distressing cognitions associated with mental ill-health such as loneliness and hopelessness. Though this rationale is expressed tentatively, it appears logical within a context of loneliness and social isolation, factors which often characterise the lives of people with ID. This may again speak to the importance of interpersonal connectedness for people with ID.

The empirical study also observed that when a relatively limited number of factors which are known to predict mental health outcomes are accounted for, people with ID appear to experience health outcomes equivalent to the general population. One tentative interpretation of this finding is that the therapy outcomes for people with ID are driven by

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factors and characteristics which are common amongst a broader subset of the population, and that these factors mediate the relationship between ID and mental health difficulties, rather than an intrinsic quality of ID. This explanation is postulated tentatively. However, the finding that treatment outcomes are broadly similar for people with and without ID once well-established predictors of treatment outcomes are controlled for is novel and is a finding which cautions against viewing people with ID in categorically distinct terms from mainstream client groups.

Simultaneously, the current findings also suggest there may be specific factors – baseline GAD-7, days to second treatment, referral duration and social deprivation score – which are associated with mental health outcomes for people with ID which are not associated with outcomes for mainstream clients. This is an important finding when trying to determine the extent to which the intrinsic qualities of ID, and the social context of ID, change the key variables associated with mental health outcomes. More research is needed to determine whether these associations can be attributed to the inherent qualities of ID, such as intellectual impairment and a reduced ability to independently problem solve, or whether this association is driven by social factors such a loneliness and isolation, which also characterise the lives of many people in the mainstream population.

Further implications for clinical practise

The current findings, particularly those of the qualitative meta-synthesis, appear relevant to ongoing debates regarding how the therapeutic alliance is conceptualised across different treatment modalities. For example, Rogers believed that conveying an attitude of warmth and a spirit of wholehearted acceptance was more important than the application of particular techniques and that therapeutic outcomes were less favourable when techniques were the dominating factor (Rogers, 2003). According to the Rogerian approach, formulation and therapeutic bond are, in some sense, primary therapeutic outcomes, as the healing quality of therapy is believed to derive from a genuine relationship which facilitates a deeper insight and awareness in the client with respect to their own thinking. As will be recalled, Beck conceptualised the therapeutic bond in more pragmatic and instrumental terms and placed greater emphasis on the cognitive-behavioural techniques in generating positive psychological change (Beck 1964; 1967; 1972). Bond is important from Beck's perspective in that it supports the client to remain motivated to engage during periods of therapy when then specific techniques are not yet generating positive change. In one sense, the current findings may be accurately understood within a Rogerian paradigm, given the centrality of the relationship and that, for many people, this appeared to be an important *outcome* of therapy. However, therapists may have had a different perspective of the same interactions and it is possible that they may have placed more emphasis on the modality-specific, technical aspects of the interaction.

Exploring this issue further, it is notable that participants across studies placed emphasis on open conversation. Ostensibly, this finding lends support to Yalom's conclusion that overly manualised approaches to therapy may block the uncertain and spontaneous encounter "necessary for effective therapy", and that therapists must develop a capacity to tolerate uncertainty when working with people with mental health difficulties (1989, p18). It is also worth recalling Kaiser's belief that successful therapy requires the therapist to adopt a mental disposition of receptiveness and that therapists must enable the person to speak freely. Yalom further stated that tensions between the need to adhere to formal schedules while also accommodating the client's spontaneous contributions may infuse conversations with "neurotic patterns" that "interfere with the establishment of communication with the patient" (Yalom, 1980. p. 403). Indeed. at least one prior study has suggested that therapists who adhered to manualised treatment protocols expressed more negative behaviours towards clients, expressing less approval, support and optimism, while relating to clients in a more

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authoritarian and defensive fashion (Asay & Lambert, 1999). However, it is well-established that both "adherence" and "competence" are important components of psychotherapeutic outcomes (Wampold, 2015). 'Adherence' refers to the delivery of specific therapy components, consistent with the content of a specific manualized protocol, and the absence of components associated with other therapeutic modalities. Therapeutic 'competence' denotes the skills with which specific therapy is delivered by therapists (Power et al, 2022). Interestingly, competence has been defined as consisting of factors such as an ability to engage a client, the competent use of treatment strategies promoting adaptive change, and an ability to judge when and when not to apply these strategies. Thus, a central part of therapeutic competency is the need to adhere to a specific modality, to ensure therapy is structured and has an overall trajectory, while simultaneously ensuring there is scope for flexibility, individual adaptation and for independent judgement. Thus, while participants stressed a preference for open conversation and the importance of the therapist's receptivity, these qualities are not incompatible with manualised approaches. Indeed, the vast majority of clients in the current meta-synthesis received therapy in accordance with specific modalities, such as CBT, DBT or CFT. A key competency of psychotherapy may thus be to integrate the client's contributions into formal treatment schedules without explicitly articulating this process to the client. Therefore, the person may have a continuous experience of genuine, open conversation within a structured therapeutic program implicitly guided by the therapist, and skilfully integrated into a manualised, evidence-based protocol. Such an ability has been identified as a meta-competency, at least within the context of CBT (Dagnan & Taylor, 2023) while several studies have likewise observed that CBT therapists are able to flexibly adapt the structure and content of manualised interventions to facilitate therapy engagement (Mignogna et al., 2018). The dichotomy between manualised and individualised/ idiosyncratic treatment schedules may therefore be overly-simplistic.

This potentially misplaced dichotomy is relevant to the debate between those who place emphasis on therapeutic modalities and techniques and those who emphasise processrelated issues and the centrality of *non-specific* factors, such as the bond between therapist and client. Proponents of the former view suggest that better treatment outcomes are dependent on the application of more efficacious treatment techniques and modalities, and that the essence of psychotherapy should be empirically supported treatments applied by therapists who closely adhere to manualised treatment schedules and guidelines under RCT conditions, and there is a substantial body of literature to support this view (Clark, Fairburn, & Wesseley, 2008; Siev et al., 2009). This contrasts with the view of theorists and practitioners such as Yalom (1980) and Rogers (2003), as well as a separate body of clinical research, which suggests that the efficacy of psychotherapy is fundamentally grounded in interpersonal and non-specific factors, particularly the affective bond between therapist and client (Hatcher, 2010; Norcross, 2011; Stiles, 2009; Wampold, 2001). Though clients often emphasised the primacy of interpersonal processes in the current study, the current findings may suggest that the dichotomy between therapeutic modality and relational bond may be misplaced as it was frequently difficult to distinguish, in any principled way, between the bond and goals and tasks. As will be recalled, the conceptual distinction between bond, goal and task was not entirely resolved within Bordin's original extrapolation of his model, with Bordin defining tasks as including "empathic understanding, communicating, interpreting [and] self-disclosing" (1979, p.254). By this definition, shared tasks within therapy entail a mutual commitment to a particular style of communication, whereby the person has a continuous experience of being listened to and valued within the context of open and honest communication about the person's difficulties. Thus, drawing conceptual distinctions between tasks and the therapeutic bond is evidently problematic. Indeed, "goals", "tasks", and "bond" are labels attached to highly complex, dynamic and interrelated processes, and it should not be assumed that these processes can be formally defined or that current linguistic categorizations can be comprehensively mapped onto them.

The finding that people with ID may desire to avoid negative evaluation, at least as much as they desire to be received positively, invites further reflection. Although much effort has been made to ensure settings such as hospital settings are "safe spaces" for people accessing services, it is worth noting that negative responses to client disclosures can indeed occur within clinical settings. This was classically highlighted by Rogers who cautioned against "declarative evaluation" within psychotherapy (Rogers, 2003). Evaluation is, of course, a key competency within clinical psychology, yet Rogers defined *declarative* evaluation in negative terms, whereby one expresses or implies their moral disapproval of a person or their actions. Research indeed suggests such negative expressions towards a client undermine therapeutic outcomes. Najavits and Strupp (1994) observed that therapists achieved more effective outcomes with their clients if they related to clients in a warm and affirming manner and expressed accurate understanding, and expressed fewer negative behaviours, including belittling and blaming, ignoring and negating, attacking and rejecting (Asay & Lambert, 1999). Such negative behaviours, experienced by several people in the current study following disclosures made outside of therapy, can be considered in Rogerian terms as a form of hierarchical evaluation, whereby one seeks to elevate their status relative to the client along some dimension, for example along a moral dimension or one based on personal or professional competence. Removing the threat of such hierarchical judgements may help create the "temporally stable and enduring framework of affective concern" which Baumeister and Leary (1995) identified as important in maintaining ongoing relational bonds.

Concluding comments

In summary, people with ID appear to experience similar rates of recovery following psychotherapy to non-ID clients once several well-established predictors of outcome are

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controlled for. This may suggest that mental health outcomes are associated with particular characteristics prevalent amongst both ID clients and a subset of clients from the mainstream population. There may thus be some justification in conceptualising people with ID as part of a broader subsection of the clinical population, rather than a discrete, categorically distinct population in and of itself. However, there also appear to be factors which are specifically associated with recovery for people with ID. Thus, the social factors which characterise the lives of people with ID, and the intrinsic impairments associated with ID, appear to warrant specific consideration and further research is needed to establish the underlying mechanisms which contribute to recovery for people with ID. Fundamentally, the extent to which people with ID are similar or dissimilar to non-ID clients may depend upon the question being asked, and the extent to which one seeks to illuminate either particularity or the gestalt.

A central implication of the current study appears to be that the maintenance of mental health is primarily an interpersonal phenomenon. These findings appear consistent with the Rogerian assumption, and Yalom's existential perspective, that reciprocal communication within the context of a genuine relationship has an ameliorating effect, particularly with respect to the complex issues which are invariably the focus of psychotherapy. However, though people often emphasised the primacy of the therapeutic relationship, the current findings imply that the dichotomy between therapeutic modality and relational bond may be misplaced. While people ID assigned primacy to the relational bond, tasks and goals appeared to also be central to the development of a bond. Likewise, therapists who understandably focus on a short-term piece of work may overlook how attending to a person and their difficulties can be a profound, novel and transformative experience for many people. The *interrelatedness* of bond, goal and task may, perhaps, represent a central active component of psychotherapy. As Yalom phrased it, "ideas are vitally empowered by intimate connections with other people" (Yalom, 2008, p.28). Such a conclusions suggest a different

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emphasis to the classic twentieth century Freudian and Jungian paradigms, which are characterised by a primary focus and emphasis on the autonomy of the individual psyche. In contrast to this classical view, the current results may be better situated in the growing body of research which places a greater emphasis on the role of interpersonal relationships and interpersonal connectedness (Baumeister & Tice, 1990; Holt-Lunstad et al., 2015).

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List of Appendices

| Search Term | Subject Headings | Variation |
|----------------------------|---|---|
| Intellectual disability | Medline: Intellectual disability CINAHL: Intellectual disability Psych Info: Intellectual developmental disorder | 'Intellectual* disab*' OR 'learning disab*' OR 'mental* disab*' OR 'mentally disabled' OR 'cognitive* disab*' OR 'mental* retard*' OR 'mental* handicap*' OR 'mentally handicapped' OR 'mental* deficien*' OR 'learning difficult*' |
| Psychological therapy | Medline: Psychotherapy CINAHL: Psychotherapy Psych Info: Psychotherapy | 'Psycho* therapy' OR 'Psycho* treatment' OR 'Psycho* intervention' OR 'Psychotherap*' OR 'psycho-therap*' OR 'therap*' |
| Service user experience | Medline: N/A CINAHL: N/A Psych Info: N/A | 'Service user experience' OR 'Service user views' OR 'Experiences' OR 'Views' OR 'Satisfaction' OR 'attitudes' OR 'Perceptions' OR 'Client attitudes' OR 'Client Satisfaction' OR Therapeutic process* OR Psychotherapeutic Process* |
| Qualitative research | Medline: Qualitative research CINAHL: Qualitative Studies Psych Info: Qualitative methods | 'Qualitative research' OR 'Qualitative method*' OR 'Thematic analys*' OR 'Interpretative Phenomenological Analys*' OR 'Grounded Theory*' OR 'Discourse Analys*' OR 'Content Analys* |

Appendix A. Terms used in systematic database search.

Appendix B. Themes not a core part of Bordin's model.

Non-specific comments relating to the therapeutic relationship

One client described how the approach of her psychologist eased her worries in the initial session in a way which appears to have been very meaningful: 'I was scared, petrified – I thought no! I can't back out – Last time I felt better. After college, I went straight to her. She was brilliant she was – she was so good" (Gifford, Evers & Walden, 2012, 117).

Sadness due to endings

Other participants described their difficulties with endings: "I wished it didn't end, but I was told about it ending, I thought Anne was a nice person..." (Khan & Beail, 2013, p.281). Another client stated: "I just don't want to stop seeing (therapist), because it'll take some time to get to see her again" (Pert et al., 2013, p.365). Other participants expressed concern that they could not maintain their progress following the end of their therapy: "I don't know but I think my anger will be back." (Pert et al., 2013, p.365). Another stated "Things take time. For a while I was doing not bad and then everything as I say happened. I just went down hill. So, right it was like I went up and then back down again. So, it could take some, some time for that to come back again you know. Like, everything's a time-consuming process. Take one day at a time, one step at a time you know" (Pert et al., 2013,

p.365). Other participants expressed a wish for an ongoing supportive relationship and felt it was necessary to demonstrate ill-health to receive continued support: "I didn't want her to stop coming. I'm not well enough for her to stop coming and I will prove I'm not" (Ramsden et al., 2015, p.253). Another participant expressed a sense of despondency in that they felt there was little prospect of change in important areas of their lives due to their intellectual disability. "But I'm still staying the same. It's really frustrating. They're all getting on with their lives but I'm never going to have a relationship I'm always going to be the odd one (out)" (Pert et al., 2013, p.365).

| | | | | Quality Appr | raisal Criteria | | | | | |
|--|--|--|--|--|---|---|---|---|---|---------------------------------|
| Studies included | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | Is the research valuable? |
| 1. Cameron, Swanton and Dagnan (2020) | + | + | + | + | + | + | + | + | + | + |
| 2. Croom et al. (2021) | + | + | + | + | + | - | + | + | + | + |
| 3. Crossland et al. (2017) | + | + | + | + | + | - | - | + | + | + |
| 4. Gifford et al. (2013) | + | + | + | + | + | + | + | + | + | + |
| 5. Hardiman et al. (2018) | + | + | + | + | + | - | + | + | + | + |
| 6. Hassiotis et al. (2013) | + | + | + | + | + | - | + | + | + | + |
| 7. Hays et al. (2007) | + | + | + | + | + | + | + | - | + | + |
| 8. Khan and Beail (2013) | + | + | + | + | + | - | - | + | + | + |
| 9. Lewis et al. (2015) | + | + | + | + | + | + | + | + | + | + |
| 10. Macdonald et al. (2003) | + | + | + | + | + | - | + | + | + | + |
| 11. MacMahon et al. (2015) | + | + | + | + | + | + | + | + | + | + |
| 12. Marwood and Hewitt (2013) | + | + | + | + | + | ? | + | + | + | + |
| 13. Merriman and Beail (2009) | + | + | + | + | + | + | + | + | + | + |
| 14. Pearson et al. (2021) | + | + | + | + | + | + | + | + | + | + |
| 15. Pert et al (2013) | + | + | + | + | + | - | + | + | + | + |
| 16. Ramsden et al. (2016) | + | + | + | + | + | + | + | + | + | + |
| 17. Roscoe et al. (2016) | + | + | + | + | + | + | + | + | + | + |

Appendix C. CASP checklist criteria

| 18. Stenfert Kroese et al. | + | + | + | + | + | - | + | + | + | + |
|----------------------------|---|---|---|---|---|---|---|---|---|---|
| (2016) | | | | | | | | | | |
| 19. Thomson and | + | + | + | + | + | + | + | + | + | + |
| Johnson (2017) | | | | | | | | | | |
| 20. Trustam, Chapman | + | + | + | + | + | ? | + | + | + | + |
| and Shanahan (2020) | | | | | | | | | | |
| ~ . | | | | | | | | | | |

+yes, - no, ? unclear

Appendix D: Continuous variables with recovery; all groups

| Variable | Rec | overed | Not rec | overed | | | | |
|---|------------------|--------|------------------|--------|---------|----------|----------|----------------|
| | Mean (n) | SD | Mean (n) | SD | t value | df | sig | Effect Size |
| Age: Unmatched People without intellectual disability | 42.60 (19649) | 15.18 | 40.54 (21580) | 15.34 | -13.681 | 40966.62 | <0.001** | -0.14 |
| Age: Matched people without intellectual disability | 33.29 (45) | 11.71 | 29.96 (82) | 11.78 | -1.527 | 125 | 0.129 | -0.28 |
| Age: Matched people with intellectual disability | 30.76 (46) | 11.63 | 31.53 (81) | 12.06 | 0.350 | 125 | 0.727 | 0.06 |
| First GAD-7 Unmatched People without intellectual disability | 13.22 (19649) | 4.36 | 12.91 (21580) | 5.86 | -6.192 | 39663.44 | <0.001** | -0.06 |
| First GAD-7: Matched people without intellectual disability | 12.87 (45) | 4.60 | 13.79 (82) | 5.58 | 0.950 | 125 | 0.344 | 0.18 |
| First GAD-7: Matched people with intellectual disability | 14.89 (46) | 3.53 | 12.76 (81) | 5.92 | -2.533 | 124.67 | 0.013* | -0.41 |
| First PHQ-9:Unmatched group without intellectual disability | 14.16 (19649) | 5.35 | 14.55 (21580) | 6.88 | 6.394 | 40258.25 | <0.001** | 0.06 |
| First PHQ-9: Matched group without intellectual disability | 13.44 (45) | 4.97 | 15.04 (82) | 6.93 | 1.495 | 116.21 | 0.138 | 0.25 |
| First PHQ-9: Matched group with intellectual disability | 14.32 (46) | 5.05 | 14.64 (81) | 7.14 | 0.290 | 118.98 | 0.772 | 0.05 |
| First WSAS: Unmatched people without intellectual disability | 17.27 (19416) | 8.81 | 18.33 (21059) | 9.92 | 11.340 | 40415.79 | <0.001** | 0.11 |

| First WSAS: Matched people without intellectual disability | 16.44 (45) | 9.33 | 19.59 (78) | 9.98 | 1.724 | 125 | 0.677 | 0.32 |
|---|-------------------|--------|-------------------|--------|--------|----------|----------|-------|
| First WSAS: Matched people with intellectual disability | 14.96 (45) | 9.35 | 17.03 (79) | 10.18 | 1.12 | 122 | 0.265 | 0.21 |
| Days to second treatment: Unmatched people without intellectual disability | 21.72 (18755) | 18.16 | 23.44 (17758) | 21.26 | 8.30 | 34964.89 | <0.001** | 0.09 |
| Days to second treatment: Matched people without intellectual disability | 19.23 (44) | 15.15 | 20.98 (52) | 17.35 | 0.53 | 94 | 0.602 | 0.11 |
| Days to second treatment: Matched people with intellectual disability | 17.85 (46) | 14.95 | 27.79 (62) | 22.72 | 2.74 | 104.66 | .007* | 0.50 |
| Total number of treatments: Unmatched people without intellectual disability | 6.73 (19525) | 4.42 | 5.34 (20918) | 4.65 | -30.93 | 40426.99 | <0.001** | -0.31 |
| Total number of treatments: Matched people without intellectual disability | 7.64 (45) | 5.37 | 5.25 (76) | 4.81 | -2.54 | 119 | 0.013* | -0.48 |
| Total number of treatments: Matched people with intellectual disability | 7.48 (46) | 4.12 | 4.66 (79) | 4.67 | .3.36 | 123 | 0.001** | -0.63 |
| Referral duration (days): Unmatched people without intellectual disability | 165.98 (19649) | 92.78 | 156.89 (21580) | 98.95 | -9.626 | 41191.45 | <0.001** | -0.10 |
| Referral duration (days): Matched people without intellectual disability | 183.16 (45) | 110.82 | 172.98 (82) | 141.37 | 418 | 125 | 0.677 | -0.08 |
| Referral duration (days): Matched people with intellectual disability | 203.83 (46) | 110.34 | 150.89 (81) | 98.27 | -2.79 | 125 | 0.006* | -0.52 |

| Social Deprivation Score: Unmatched people without intellectual disability | 21.66 (17895) | 7.64 | 22.43 (19700) | 7.66 | 9.757 | 37263.21 | <0.001** | 0.10 |
|--|--------------------|-------|--------------------|------|--------|-----------|----------|-------|
| Social Deprivation Score: Matched people without intellectual disability | 22.73 (44) | 72.56 | 23.06 (69) | 7.37 | 0.236 | 111 | 0.814 | 0.05 |
| Social Deprivation Score: Matched people with intellectual disability | 20.74 (46) | 7.37 | 24.72 (81) | 7.97 | 2.78 | 125 | 0.006* | 0.51 |
| Referral year: Unmatched people without intellectual disability | 19649 (2014.18) | 3.01 | 21580 (2014.80) | 3.08 | -11.83 | 41023.166 | <0.001** | -0.12 |
| Referral year: Matched people without intellectual disability | 2013.73 (45) | 3.17 | 2013.17 (82) | 2.71 | -1.053 | 125 | 0.294 | -0.20 |
| Referral year: Matched people with intellectual disability | 2013.67 (46) | 2.99 | 2014.14 (81) | 3.15 | .809 | 125 | 0.42 | 0.15 |

| Variable | Recovery | | Not recovery | | | | | |
|--|--------------------------|---------------------------------|------------------------------------|-----------------------------------|---------------|----|-----------|-----------------------------|
| | Yes (% within recovered) | No (% within recovered) | Yes (% within not recovered) | No (% within not recovered) | Chi Square | df | sig | OR (95% CI) |
| Gender (Yes=Female; No=Male) Unmatched people without intellectual disability | 12455 (63.4%) | 7190 (36.6%) | 13808 (64.0%) | 7769 (36%) | 1.568 | 1 | 0.211 | 0.98 (0.94 - 1.02) |
| Gender (Yes=Female; No=Male) Matched people without intellectual disability | 23 (51.1%) | 22 (48.9%) | 47 (57.3) | 35 (42.5) | 0.452 | 1 | 0.501 | 0.779 (0.375 – 1.616) |
| Gender (Yes=Female; No=Male) Matched people with intellectual disability | 25 (54.3%) | 21 (45.7%) | 45 (55.6%) | 36 (44.4%) | 0.01 | 1 | 0.99 | 0.952 (0.460 – 1.971) |
| High/Low treatment intensity (Yes = PWP; No = HIT) Unmatched group without intellectual disability | 16701 (85%) | 2932 (14.9%) | 17852 (82.8%) | 3705 (17.2%) | 38.585 | 1 | <0.001*** | 0.85 (0.80 – 0.89) |
| High/Low treatment intensity (Yes = PWP; No = HIT) Matched people without intellectual disability | 8 (17.8%) | 37 (82.8%) | 16 (19.5%) | 66 (80.5%) | 0.57 | 1 | 0.811 | 0.892 (0.349 – 2.282) |

Appendix E: Categorical variables comparison for people that do and do not recover; all groups

| High/Low treatment intensity (Yes = PWP; No = HIT) Matched people with intellectual disability | 31 (67.4%) | 15 (32.6%) | 62 (76.5%) | 19 (23.5%) | 1.25 | 1 | 0.26 | 1.579 (0.708 – 3.523) |
|---|------------------|--------------|---------------|---------------|----------|---|------------|-------------------------------|
| Long-Term Conditions (Yes/No) Unmatched group without intellectual disability | 3937 (46%) | 4627 (54%) | 15712 (51.9%) | 16953 (48.1%) | 12.328 | 1 | < 0.001 | 0.918 (0.875 – 0.963) |
| Long-Term Conditions (Yes/No) Matched group without intellectual disability | 3 (6.7%) | 42 (93.3%) | 14 (17.1%) | 68 (82.9%) | 2.714 | 1 | 0.099 | 0.347 (0.94 – 1.279) |
| Long-Term Conditions (Yes/No) Matched people with intellectual disability | 17 (37.0%) | 29 (63.0%) | 24 (29.6%) | 57 (70.4%) | 0.72 | 1 | 0.40 | 1.392 (0.648 – 2.993) |
| Discharge planned (Yes/No) Unmatched group without intellectual disability | 17035 (86.7%) | 2614 (13.3%) | 10143 (47%) | 11437 (53%) | 7213.406 | 1 | < 0.001*** | 7.348 (6.996 – 7.718) |
| Discharge planned (Yes/No) Matched group without intellectual disability | 39 (86.7%) | 6 (13.3%) | 29 (35.4%) | 53 (64.6%) | 30.741 | 1 | <0.001*** | 11.879 (4.497 – 31.382) |
| Discharge planned (Yes/No) Matched people with intellectual disability | 42 (91.3%) | 4 (8.7%) | 37 (46.8%) | 42 (53.2%) | 24.72 | 1 | <0.001*** | 12.486 (4.095 – 38.074) |

| Relationship (Yes/No) Unmatched group without intellectual disability | 12066 (51.1%) | 11562 (48.9%) | 7421 (43%) | 9824 (57%) | 257.923 | 1 | <0.001*** | 1.382 (1.328 – 1.437) |
|---|------------------|---------------|---------------|---------------|---------|---|-----------|-----------------------------|
| Relationship (Yes/No) | 29 (64.4%) | 16 (35.6%) | 42 (51.2%) | 40 (48.8%) | 2.061 | 1 | 0.151 | 1.726 |
| Matched group without intellectual disability | | | | | | | | (0.817 – 3.648) |
| Relationship (Yes/No) | 12 (27.9%) | 31 (72.1%) | 23 (29.1%) | 56 (70.9%) | 0.020 | 1 | 0.888 | 0.942 |
| Matched people with intellectual disability | | | | | | | | (0.413 – 2.149) |
| Psychotropic medication (Yes/No) | 8969 (46.2%) | 10440 (53.8%) | 10082 (47.6%) | 11107 (52.4%) | 7.643 | 1 | 0.006* | 0.95 (0.91 – |
| Unmatched people without intellectual disability | | | | | | | | 0.984) |
| Psychotropic medication (Yes/No) | 22 (50%) | 22 (50%) | 39 (48.1%) | 42 (51.9%) | 0.039 | 1 | 0.843 | 1.077 (0.517 – |
| Matched people without intellectual disability | | | | | | | | 2.244) |
| Psychotropic medication (Yes/No) | 19 (42.2%) | 26 (57.8%) | 38 (48.7%) | 40 (51.3%) | 0.484 | 1 | 0.487 | 0.769 (0.367 – |
| Matched people with intellectual disability | | | | | | | | 1.612) |
| Employed (Yes/No) | 13984 | 5592 (28.6%) | 13039 (60.7%) | 8432 (39.3%) | 521.802 | 1 | <0.001*** | 1.617 |
| Unmatched people without intellectual disability | (71.4%) | | | | | | | (1.552 – 1.685) |

| Employed (Yes/No) | 34 (75.6%) | 11 (24.4%) | 50 (61%) | 32 (39%) | 2.758 | 1 | 0.97 | 1.978 |
|--|------------|------------|------------|------------|-------|---|-------|--------------------|
| Matched people without intellectual disability | | | | | | | | (0.878 – 4.455) |
| Employed (Yes/No) | 15 (32.6%) | 31 (67.4%) | 17 (21.8%) | 61 (78.2%) | 1.767 | 1 | 0.184 | 1.736 |
| Matched people with intellectual disability | | | | | | | | (0.766 – 3.934) |

Appendix F

PLOS ONE

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|---------------|--|
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| | Keep abbreviati | ons to a minimum. | | | | | |
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| | Note: A DOI number for the full-text article is acceptable as an alternative to or in addition to traditional volume and page numbers. When providing a DOI, adhere to the format in the example above with both the label and full DOI included at the end of the reference (doi: 10.1016/j.molimm.2014.11.005). Do not provide a shortened DOI or the URL. |
| Accepted, unpublished articles | Same as published articles, but substitute "Forthcoming" for page numbers or DOI. |
| Online articles | Huynen MMTE, Martens P, Hilderlink HBM. The health impacts of globalisation: a conceptual framework. Global Health. 2005;1: 14. Available from: <u>http://www.globalizationandhealth.com/content/1/1/14</u> |
| Books | Bates B. Bargaining for life: A social history of tuberculosis. 1st ed. Philadelphia: University of Pennsylvania Press; 1992. |

| Source | Format | |
|-------------------------|---|--|
| Book chapters | Hansen B. New York City epidemics and history for the public. In: Harden VA, Risse GB, | |
| | editors. AIDS and the historian. Bethesda: National Institutes of Health; 1991. pp. 21-28. | |
| Deposited | Krick T, Shub DA, Verstraete N, Ferreiro DU, Alonso LG, Shub M, et al. Amino acid | |
| articles (preprints, e- | metabolism conflicts with protein diversity. arXiv:1403.3301v1 [Preprint]. 2014 [cited 2014 | |
| prints, or arXiv) | March 17]. Available from: <u>https://128.84.21.199/abs/1403.3301v1</u> | |
| | Kording KP, Mensh B. Ten simple rules for structuring papers. BioRxiv [Preprint]. 2016 bioRxiv 088278 [posted 2016 Nov 28; revised 2016 Dec 14; revised 2016 Dec 15; cited 2017 Feb 9]: [12 p.]. Available from: <u>https://www.biorxiv.org/content/10.1101/088278v5</u> doi: 10.1101/088278 | |
| Published media | Fountain H. For Already Vulnerable Penguins, Study Finds Climate Change Is Another Danger. | |
| (print or online | The New York Times. 2014 Jan 29 [Cited 2014 March 17]. Available | |
| newspapers and | from: http://www.nytimes.com/2014/01/30/science/earth/climate-change-taking-toll-on- | |
| magazine articles) | penguins-study-finds.html | |
| New media (blogs, | Allen L. Announcing PLOS Blogs. 2010 Sep 1 [cited 17 March 2014]. In: PLOS Blogs | |
| web sites, or other | [Internet]. San Francisco: PLOS 2006 [about 2 screens]. Available | |
| written works) | trom: <u>http://blogs.plos.org/plos/2010/09/announcing-plos-blogs/</u> . | |
| Masters' theses or | Wells A. Exploring the development of the independent, electronic, scholarly journal. M.Sc. | |
| doctoral | Thesis, The University of Sheffield. 1999. Available from: <u>http://cumincad.scix.net/cgi-</u> | |
| dissertations | bin/works/Show?2e09 | |
| Databases and | Roberts SB. QPX Genome Browser Feature Tracks; 2013 [cited 2013 Oct 5]. Database: figshare | |
| repositories | [Internet]. Available | |
| (Figshare, arXiv) | from: http://figshare.com/articles/QPX_Genome_Browser_Feature_Tracks//01214 | |
| Multimedia (videos, | Hitchcock A, producer and director. Rear Window [Film]; 1954. Los Angeles: MGM. | |
| movies, or TV | | |
| snows) | | |
| Supporting information | | |

Authors can submit essential supporting files and multimedia files along with their manuscripts. All supporting information will be subject to peer review. All file types can be submitted, but files must be smaller than 20 MB in size.

Authors may use almost any description as the item name for a supporting information file as long as it contains an "S" and number. For example, "S1 Appendix," and "S2 Appendix," "S1 Table" and "S2 Table," and so forth.

Supporting information files are published exactly as provided, and are not copyedited.

Supporting information captions

List supporting information captions at the end of the manuscript file. Do not submit captions in a separate file.

The file number and name are required in a caption, and we highly recommend including a one-line title as well. You may also include a legend in your caption, but it is not required.

Example caption

S1 Text. Title is strongly recommended. Legend is optional. In-text citations

We recommend that you cite supporting information in the manuscript text, but this is not a requirement. If you cite supporting information in the text, citations do not need to be in numerical order.

Read the <u>supporting information guidelines</u> for more details about submitting supporting information and multimedia files. **Figures and tables**

Figures

Do not include figures in the main manuscript file. Each figure must be prepared and submitted as an individual file.

Cite figures in ascending numeric order at first appearance in the manuscript file.

<u>Read the guidelines for figures</u> and <u>requirements for reporting blot and gel results</u>. Figure captions

Figure captions must be inserted in the text of the manuscript, immediately following the paragraph in which the figure is first cited (read order). Do not include captions as part of the figure files themselves or submit them in a separate document.

At a minimum, include the following in your figure captions:

- A figure label with Arabic numerals, and "Figure" abbreviated to "Fig" (e.g. Fig 1, Fig 2, Fig 3, etc). Match the label of your figure with the name of the file uploaded at submission (e.g. a figure citation of "Fig 1" must refer to a figure file named "Fig1.tif").
- A concise, descriptive title

The caption may also include a legend as needed.

<u>Read more about figure captions</u>. Tables

Cite tables in ascending numeric order upon first appearance in the manuscript file.

Place each table in your manuscript file directly after the paragraph in which it is first cited (read order). Do not submit your tables in separate files.

Tables require a label (e.g., "Table 1") and brief descriptive title to be placed above the table. Place legends, footnotes, and other text below the table.

Read the guidelines for tables. Statistical reporting

Manuscripts submitted to *PLOS ONE* are expected to report statistical methods in sufficient detail for others to replicate the analysis performed. Ensure that results are rigorously reported in accordance with community standards and that statistical methods employed are appropriate for the study design.

Consult the following resources for additional guidance:

- <u>SAMPL guidelines</u>, for general guidance on statistical reporting
- <u>PLOS ONE guidelines</u>, for clinical trials requirements
- <u>PLOS ONE guidelines</u>, for systematic review and meta-analysis requirements
- <u>EQUATOR</u>, for specific reporting guidelines for a range of other study types

Reporting of statistical methods

In the methods, include a section on statistical analysis that reports a detailed description of the statistical methods. In this section:

- List the name and version of any software package used, alongside any relevant references
- Describe technical details or procedures required to reproduce the analysis
- Provide the repository identifier for any code used in the analysis (See our <u>code-sharing policy</u>.)

Statistical reporting guidelines:

- Identify research design and independent variables as being between- or within-subjects
- For pre-processed data:
 - Describe any analysis carried out to confirm the data meets the assumptions of the analysis performed (e.g. linearity, co-linearity, normality of the distribution).
 - If data were transformed include this information, with a reason for doing so and a description of the transformation performed
- Provide details of how outliers were treated and your analysis, both with the full dataset and with the outliers removed

- If relevant, describe how missing/excluded data were handled
- Define the threshold for significance (alpha)
- If appropriate, provide sample sizes, along with a description of how they were determined. If a sample size calculation was performed, specify the inputs for power, effect size and alpha. Where relevant, report the number of independent replications for each experiment.
- For analyses of variance (ANOVAs), detail any post hoc tests that were performed
- Include details of any corrections applied to account for multiple comparisons. If corrections were not applied, include a justification for not doing so
- Describe all options for statistical procedures. For example, if t-tests were performed, state whether these were one- or two-tailed. Include details of the type of t-test conducted (e.g. one sample, within/between-subjects).
- For step-wise multiple regression analyses:
 - Report the alpha level used
 - Discuss whether the variables were assessed for collinearity and interaction
 - Describe the variable selection process by which the final model was developed (e.g., forward-stepwise; best subset). <u>See SAMPL guidelines</u>.
- For Bayesian analysis explain the choice of prior trial probabilities and how they were selected. Markov chain Monte Carlo settings should be reported.

Reporting of statistical results

Results must be rigorously and appropriately reported, in keeping with community standards.

- Units of measurement. Clearly define measurement units in all tables and figures.
- **Properties of distribution.** It should be clear from the text which measures of variance (standard deviation, standard error of the mean, confidence intervals) and central tendency (mean, median) are being presented.
- **Regression analyses.** Include the full results of any regression analysis performed as a supplementary file. Include all estimated regression coefficients, their standard error, p-values, and confidence intervals, as well as the measures of goodness of fit.
- **Reporting parameters.** Test statistics (F/t/r) and associated degrees of freedom should be provided. Effect sizes and confidence intervals should be reported where appropriate. If percentages are provided, the numerator and denominator should also be given.
- **P-values.** Report exact p-values for all values greater than or equal to 0.001. P-values less than 0.001 may be expressed as p < 0.001, or as exponentials in studies of genetic associations.
- **Displaying data in plots.** Format plots so that they accurately depict the sample distribution. 3D effects in plots can bias and hinder interpretation of values, so avoid them in cases where regular plots are sufficient to display the data.
- **Open data.** As explained in PLOS's <u>Data Policy</u>, be sure to make individual data points, underlying graphs and summary statistics available at the time of publication. Data can be deposited in a repository or included within the Supporting Information files.

Data reporting

All data and related metadata underlying the findings reported in a submitted manuscript should be deposited in an appropriate public repository, unless already provided as part of the submitted article.

See instructions on providing underlying data to support blot and gel results.

Read our policy on data availability.

Repositories may be either subject-specific (where these exist) and accept specific types of structured data, or generalist repositories that accept multiple data types. We recommend that authors select repositories appropriate to their field. Repositories may be subject-specific (e.g., GenBank for sequences and PDB for structures), general, or institutional, as long as DOIs or accession numbers are provided and the data are at least as open as CC BY. Authors are encouraged to select repositories that meet accepted criteria as trustworthy digital repositories, such as criteria of the Centre for Research Libraries or Data Seal of Approval. Large, international databases are more likely to persist than small, local ones.

See our list of recommended repositories.

To support data sharing and author compliance of the PLOS data policy, we have integrated our submission process with a select set of data repositories. The list is neither representative nor exhaustive of the suitable repositories available to authors. Current repository integration partners include <u>Dryad</u> and <u>FlowRepository</u>. Please contact <u>data@plos.org</u> to make recommendations for further partnerships.

Instructions for PLOS submissions with data deposited in an integration partner repository:

- Deposit data in the integrated repository of choice.
- Once deposition is final and complete, the repository will provide you with a dataset DOI (provisional) and private URL for reviewers to gain access to the data.
- Enter the given data DOI into the full Data Availability Statement, which is requested in the Additional Information section of the PLOS submission form. Then provide the URL passcode in the Attach Files section.

If you have any questions, please email us.

Accession numbers

All appropriate data sets, images, and information should be deposited in an appropriate public repository. <u>See our list of recommended repositories</u>.

Accession numbers (and version numbers, if appropriate) should be provided in the Data Availability Statement. Accession numbers or a citation to the DOI should also be provided when the data set is mentioned within the manuscript.

In some cases authors may not be able to obtain accession numbers of DOIs until the manuscript is accepted; in these cases, the authors must provide these numbers at acceptance. In all other cases, these numbers must be provided at full submission.

Identifiers

As much as possible, please provide accession numbers or identifiers for all entities such as genes, proteins, mutants, diseases, etc., for which there is an entry in a public database, for example:

• Ensembl

- Entrez Gene
- <u>FlyBase</u>
- <u>InterPro</u>
- Mouse Genome Database (MGD)
- Online Mendelian Inheritance in Man (OMIM)
- <u>PubChem</u>

Identifiers should be provided in parentheses after the entity on first use.

Striking Image

You can choose to upload a "Striking Image" that we may use to represent your article online in places like the journal homepage or in search results.

The striking image must be derived from a figure or supporting information file from the submission, i.e., a cropped portion of an image or the entire image. Striking images should ideally be high resolution, eye-catching, single panel images, and should ideally avoid containing added details such as text, scale bars, and arrows.

If no striking image is uploaded, we will designate a figure from the submission as the striking image.

Striking images should not contain potentially identifying images of people. <u>Read our policy on identifying information</u>.

<u>The PLOS licenses and copyright policy also applies to striking images.</u> Additional Information Requested at Submission

Financial Disclosure Statement

This information should describe sources of funding that have supported the work. It is important to gather these details prior to submission because your financial disclosure statement cannot be changed after initial submission without journal approval. If your manuscript is published, your statement will appear in the Funding section of the article.

Enter this statement in the Financial Disclosure section of the submission form. Do not include it in your manuscript file.

The statement should include:

- Specific grant numbers
- Initials of authors who received each award
- Full names of commercial companies that funded the study or authors
- Initials of authors who received salary or other funding from commercial companies
- URLs to sponsors' websites

Also state whether any sponsors or funders (other than the named authors) played any role in:

• Study design

- Data collection and analysis
- Decision to publish
- Preparation of the manuscript

If they had no role in the research, include this sentence: "The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript."

If the study was unfunded, include this sentence as the Financial Disclosure statement: "The author(s) received no specific funding for this work."

Read our policy on disclosure of funding sources. Competing interests

This information should not be in your manuscript file; you will provide it via our submission system.

All potential competing interests must be declared in full. If the submission is related to any patents, patent applications, or products in development or for market, these details, including patent numbers and titles, must be disclosed in full.

Read our policy on competing interests. Manuscripts disputing published work

For manuscripts disputing previously published work, it is *PLOS ONE* policy to invite a signed review by the disputed author during the peer review process. This procedure is aimed at ensuring a thorough, transparent, and productive review process.

If the disputed author chooses to submit a review, it must be returned in a timely fashion and contain a full declaration of all competing interests. The Academic Editor will consider any such reviews in light of the competing interest.

Authors submitting manuscripts disputing previous work should explain the relationship between the manuscripts in their cover letter, and will be required to confirm that they accept the conditions of this review policy before the manuscript is considered further.

Related Manuscripts

Upon submission, authors must confirm that the manuscript, or any related manuscript, is not currently under consideration or accepted elsewhere. If related work has been submitted to *PLOS ONE* or elsewhere, authors must include a copy with the submitted article. Reviewers will be asked to comment on the overlap between related submissions.

We strongly discourage the unnecessary division of related work into separate manuscripts, and we will not consider manuscripts that are divided into "parts." Each submission to *PLOS ONE* must be written as an independent unit and should not rely on any work that has not already been accepted for publication. If related manuscripts are submitted to *PLOS ONE*, the authors may be advised to combine them into a single manuscript at the editor's discretion.

Read our policies on <u>related manuscripts</u>. **Preprints**

PLOS encourages authors to post preprints to accelerate the dissemination of research. Posting a manuscript on a preprint server does not impact consideration of the manuscript at any PLOS journal.

Authors posting preprints on <u>bioRxiv</u> or <u>medRxiv</u> can choose to concurrently submit their manuscripts to relevant PLOS journals through the direct transfer service.

Authors submitting manuscripts in the life and health sciences to *PLOS ONE* may choose to have PLOS forward their submission to bioRxiv or medRxiv, depending on the scope of the paper, for consideration for posting as a preprint.

Read more about preprints.

Learn how to post a preprint to bioRxiv or medRxiv at *PLOS ONE*. Guidelines for Specific Study Types

Study design, reporting, and analyses are assessed against all relevant research and methodological technique standards held by the community. Guidelines for specific study types are outlined below.

Registered Reports

Submission and format requirements for <u>Registered Report Protocols and Registered Reports</u> are similar to those for a regular submission and may be specific to your study type. For instance, if your Registered Report Protocol submission is about a Clinical Trial or a Systematic Review, follow the appropriate guidelines.

For Registered Report Protocols:

- Provide enough methodological detail to make the study reproducible and replicable
- Confirm that data will be made available upon study completion in keeping with the <u>PLOS Data</u> <u>policy</u>
- Include ethical approval or waivers, if applicable
- Preliminary or pilot data may be included, but only if necessary to support the feasibility of the study or as a proof of principle
- For meta-analyses or Clinical Trials, use the protocol-specific reporting guidelines <u>PRISMA-</u> <u>P</u> or <u>SPIRIT</u> respectively

For more guidance on format and presentation of a protocol, consult the <u>sample template hosted by the Open</u> <u>Science Framework</u>. <u>Discipline-specific and study-specific templates</u> are also available.

If data need to be collected, modified or processed specifically for your study, or if participants need to be recruited specifically for your study, then it should occur only after your Registered Report Protocol is accepted for publication.

For Registered Report Research Articles:

- Report the results of all planned analyses and, if relevant, detail and justify all deviations from the protocol.
- The manuscript may also contain exploratory, unplanned analyses.

Read more about Registered Report framework.

Human subjects research

All research involving human participants must have been approved by the authors' Institutional Review Board (IRB) or by equivalent ethics committee(s), and must have been conducted according to the principles expressed in the <u>Declaration of Helsinki</u>. Authors should be able to submit, upon request, a statement from the IRB or ethics committee indicating approval of the research. We reserve the right to reject work that we believe has not been conducted to a high ethical standard, even when formal approval has been obtained.

Subjects must have been properly instructed and have indicated that they consent to participate by signing the appropriate informed consent paperwork. Authors may be asked to submit a blank, sample copy of a subject consent form. If consent was verbal instead of written, or if consent could not be obtained, the authors must explain the reason in the manuscript, and the use of verbal consent or the lack of consent must have been approved by the IRB or ethics committee.

All efforts should be made to protect patient privacy and anonymity. Identifying information, including photos, should not be included in the manuscript unless the information is crucial and the individual has provided written consent by completing the <u>Consent Form for Publication in a PLOS Journal (PDF)</u>. Download additional translations of the form <u>here</u>. More information about patient privacy, anonymity, and informed consent can be found in the <u>International Committee of Medical Journal Editors</u> (ICMJE) <u>Privacy and Confidentiality guidelines</u>.

Manuscripts should conform to the following reporting guidelines:

- Studies of diagnostic accuracy: <u>STARD</u>
- Observational studies: <u>STROBE</u>
- Microarray experiments: <u>MIAME</u>
- Other types of health-related research: Consult the <u>EQUATOR</u> web site for appropriate reporting guidelines

Methods sections of papers on research using human subjects or samples must include ethics statements that specify:

- The name of the approving institutional review board or equivalent committee(s). If approval was not obtained, the authors must provide a detailed statement explaining why it was not needed
- Whether informed consent was written or oral. If informed consent was oral, it must be stated in the manuscript:
 - Why written consent could not be obtained
 - o That the Institutional Review Board (IRB) approved use of oral consent
 - How oral consent was documented

For studies involving humans categorized by race/ethnicity, age, disease/disabilities, religion, sex/gender, sexual orientation, or other socially constructed groupings, authors should:

- Explicitly describe their methods of categorizing human populations
- Define categories in as much detail as the study protocol allows
- Justify their choices of definitions and categories, including for example whether any rules of human categorization were required by their funding agency
- Explain whether (and if so, how) they controlled for confounding variables such as socioeconomic status, nutrition, environmental exposures, or similar factors in their analysis

In addition, outmoded terms and potentially stigmatizing labels should be changed to more current, acceptable terminology. Examples: "Caucasian" should be changed to "white" or "of [Western] European descent" (as appropriate); "cancer victims" should be changed to "patients with cancer."

For papers that include identifying, or potentially identifying, information, authors must <u>download</u> <u>the Consent Form for Publication in a PLOS Journal</u>, which the individual, parent, or guardian must sign once they have read the paper and been informed about the terms of PLOS open-access license. The signed consent form should not be submitted with the manuscript, but authors should securely file it in the individual's case notes and the methods section of the manuscript should explicitly state that consent authorization for publication is on file, using wording like:

The individual in this manuscript has given written informed consent (as outlined in PLOS consent form) to publish these case details.

For more information about *PLOS ONE* policies regarding human subjects research, see the <u>Publication</u> <u>Criteria</u> and <u>Editorial Policies</u>.

Manuscripts describing observational clinical studies are subject to all policies regarding <u>human</u> <u>research</u> and community standards for reporting observational research as outlined by the <u>STROBE</u> statement. Furthermore, authors submitting work of this nature should pay special attention to the following requirements:

- If the submitted manuscript is very similar to previous work, authors must provide a sound scientific rationale for the submitted work and clearly reference and discuss the existing literature.
- The sampling strategy and eligibility criteria of enrolled subjects should be described in sufficient detail.
- Sample size calculations should be justified with relevant inputs defined.
- Independent and dependent variables considered for statistical analysis should be clearly defined and justified.
- The validity and reliability testing of self-developed data collection tools should be reported.
- Conclusions should be appropriate for the study design, with indications on how the study results will contribute to the base of academic knowledge.

Clinical trials

Clinical trials are subject to all <u>policies regarding human research</u>. *PLOS ONE* follows the <u>World Health</u> <u>Organization's (WHO) definition of a clinical trial</u>:

A clinical trial is any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes [...] Interventions include but are not restricted to drugs, cells and other biological products, surgical procedures, radiologic procedures, devices, behavioural treatments, process-of-care changes, preventive care, etc. All clinical trials must be registered in one of the publicly-accessible registries approved by the <u>WHO</u> or <u>ICMJE</u> (International Committee of Medical Journal Editors). Authors must provide the trial registration number. Prior disclosure of results on a clinical trial registry site will not affect consideration for publication. We reserve the right to inform authors' institutions or ethics committees, and to reject the manuscript, if we become aware of unregistered trials. *PLOS ONE* supports prospective trial registration (i.e. before participant recruitment has begun) as recommended by the ICMJE's <u>clinical trial registration policy</u>. Where trials were not publicly registered before participant recruitment began, authors must:

- Register all related clinical trials and confirm they have done so in the Methods section
- Explain in the Methods the reason for failing to register before participant recruitment

Clinical trials must be reported according to the relevant reporting guidelines, i.e. <u>CONSORT</u> for randomized controlled trials, <u>TREND</u> for non-randomized trials, and <u>other specialized guidelines</u> as appropriate. The intervention should be described according to the requirements of the <u>TIDieR checklist and guide</u>. Submissions must also include the study protocol as supporting information, which will be published with the manuscript if accepted.

Authors of manuscripts describing the results of clinical trials must adhere to the <u>CONSORT</u> reporting guidelines appropriate to their trial design, available on the <u>CONSORT Statement web site</u>. Before the paper can enter peer review, authors must:

- The name of the registry and the registration number must be included in the Abstract.
- Provide a copy of the trial protocol as approved by the ethics committee and a completed <u>CONSORT</u> <u>checklist</u> as supporting information (which will be published alongside the paper, if accepted). This should be named S1 CONSORT Checklist.
- Include the <u>CONSORT flow diagram</u> as the manuscript's "Fig 1"

Any deviation from the trial protocol must be explained in the paper. Authors must explicitly discuss informed consent in their paper, and we reserve the right to ask for a copy of the patient consent form.

The name of the registry and the registry number must be provided in the Abstract. If the trial is registered in more than one location, please provide all relevant registry names and numbers.

Lab Protocols

<u>Lab Protocols</u> consist of two interlinked components: a step-by-step protocol hosted on <u>protocols.io</u>, and a peer-reviewed article in *PLOS ONE* that contextualises the protocol.

protocols.io is a secure platform for developing and sharing reproducible methods. It enables scientists to make, exchange, improve, and discuss protocols for specific experimental procedures. The platform provides specialized tools for communicating technical details, including reagents, measurements, and formulae.

The *PLOS ONE* article component must comply with the general *PLOS ONE* submission guidelines (detailed above) and <u>criteria for publication</u>. In addition, the *PLOS ONE* article component should:

- Describe the value that the protocol adds to the published literature. Lab Protocols describing routine methods or extensions and modifications of routine methods that add little value to the published literature will not be considered for publication.
- Provide evidence that the protocol works, by either:
 - Linking, in the Introduction section, to at least one supporting peer-reviewed publication in which the protocol was applied to generate data.

- Providing validation or benchmarking data, which demonstrates that the underlying method achieves its intended purpose.
- Provide the step-by-step protocol as a supporting information (S1) file.

Download a Lab Protocol article template

We encourage you to post your protocol to the protocols.io platform before submitting your manuscript to *PLOS ONE*. Posting your protocol prior to submission is not considered prior publication by *PLOS ONE* and will not affect your eligibility to publish a Lab Protocol.

Authors submitting a Lab Protocol can also use protocols.io's <u>protocol entry service</u> at no cost: the team at protocols.io will enter your protocol for you and format it in a way that takes advantage of the platform's features. You will have an opportunity to review and make further changes before your protocol is shared with anyone else.

If you would like to use protocols.io's protocol entry service in connection with a Lab Protocol submission, please contact plosone@plos.org to request the customer code.

If you prefer to submit your manuscript to *PLOS ONE* before posting your protocol to protocols.io, then you must still provide your step-by-step protocol as a <u>supporting information</u> (S1) file in a format of your choosing. You will be expected to replace this file with a protocols.io PDF later in the editorial process.

Study Protocols

<u>Study Protocols</u> describe plans for conducting research projects and consist of a single article on *PLOS ONE*.

Study Protocols must comply with the *PLOS ONE* general submission guidelines (detailed above in this article) and any guidelines specific to the related research study type. In addition, the protocol must:

- Relate to a research study that has not yet generated results.
- Be submitted before recruitment of participants or collection of data for the study is complete.
- Meet the same standards for <u>ethics of experimentation and research integrity</u> as the research study. If it involves <u>human</u> or <u>animal</u> subjects, <u>cell lines</u> or <u>field sampling</u>, or has <u>potential biosafety</u> <u>implications</u>, prior approval from the relevant ethics body must be obtained prior to submission. Please contact us if you have a valid reason for not obtaining approval.

Additional prerequisites apply for these study types:

- <u>Clinical trials</u>:
 - The trial must be registered prior to submission of your protocol in one of the publicly accessible registries approved by the WHO or ICMJE (International Committee of Medical Journal Editors).
 - The name of the registry and the trial or study registration number must be included in the Abstract.
 - A copy of the protocol that was approved by the ethics committee must be submitted as a supplementary information file. Please provide an additional English translation if the original document is not in English. Please note that the protocol will be published with the manuscript if accepted.

- A SPIRIT <u>schedule of enrollment, interventions, and assessments</u> must be included as the manuscript's Figure 1, and a completed <u>SPIRIT checklist</u> must be uploaded as Supporting Information file S1.
- <u>Systematic reviews and meta-analyses</u>:
 - A completed <u>PRISMA-P checklist</u> must be provided as a supporting information (SI) file. See <u>PRISMA-P Explanation and Elaboration</u> for more information on completing your checklist.

Study Protocols must also comply with general *PLOS ONE* <u>criteria for publication</u> and in addition you should:

- include the word "Protocol" in your Title.
- include a detailed description of the planned study in the Materials and Methods section. This should provide sufficient methodological detail for the protocol to be reproducible and replicable. Your description should cover all relevant and applicable facts and hypothesis, including:
 - the aim, design, and settling
 - \circ the sample size calculation
 - how data saturation will be determined (for qualitative studies)
 - the characteristics of participants e.g., inclusion and exclusion criteria, sample selection criteria, variables to be measured, randomization and blinding criteria (where applicable), and how informed consent will be obtained
 - how materials will be selected and used e.g., where and how they will be sourced, the processes, interventions, or comparisons to be used, the outcomes to be measured, and when and how they will be measured
 - the data management plan
 - safety considerations
 - the type of data and statistical analyses to be used
 - the status and timeline of the study, including whether participant recruitment or data collection has begun
 - where and when the data will be made available. See our <u>Data Availability policy</u> for more.
- include an analysis of preliminary or pilot data, only if it is necessary to support the feasibility of the study or as a proof of principle. This is optional.
- we encourage authors you to register with <u>OSF</u> and provide the your registration number in the Materials and Methods section. This is optional.
- optionally add any other SI files, figures or tables that elaborate or authenticate the protocol: e.g., any reporting checklists applicable to your study type.

Read the supporting information guidelines for more details about adding SI files.

Download <u>our sample Study Protocol template</u> or an OSF <u>discipline or study-specific template</u>. Study Protocols are subject to the same <u>editorial</u> and <u>peer review</u> process as all other articles, and are eligible for both <u>signed and published peer review</u>. You can expedite the review process by providing:

- proof of external funding. This is typically your funding approval letter and a list of the names and credentials of the funders who conducted the external peer review of the protocol. Include an English translation if needed.
- proof of ethics approval (if required). This is typically the approval or waiver letter from the relevant ethics body and a copy of the protocol approved by this body.

The proof of external funding and approval or waiver letter are used for internal purposes and do not form part of the published Study Protocol.

Expedited review is conducted by an internal Staff Editor only and bypasses the external review process.

If the Study Protocol describes a replication study or involves re-analysis of published work, we will invite the author of the initial or replicated study to provide a signed review.

We encourage you to share your Study Protocol with other researchers, either before or after submission. You can publish it on your website or <u>protocols.io</u>, or submit it for posting on <u>medRxiv</u> or another preprint server.

Animal research

All research involving vertebrates or cephalopods must have approval from the authors' Institutional Animal Care and Use Committee (IACUC) or equivalent ethics committee(s), and must have been conducted according to applicable national and international guidelines. Approval must be received prior to beginning research.

Manuscripts reporting animal research must state in the Methods section:

- The full name of the relevant ethics committee that approved the work, and the associated permit number(s).
- Where ethical approval is not required, the manuscript should include a clear statement of this and the reason why. Provide any relevant regulations under which the study is exempt from the requirement for approval.
- Relevant details of steps taken to ameliorate animal suffering.

Example ethics statement

This study was carried out in strict accordance with the recommendations in the Guide for the Care and Use of Laboratory Animals of the National Institutes of Health. The protocol was approved by the Committee on the Ethics of Animal Experiments of the University of Minnesota (Protocol Number: 27-2956). All surgery was performed under sodium pentobarbital anesthesia, and all efforts were made to minimize suffering.

Authors should always state the organism(s) studied in the Abstract. Where the study may be confused as pertaining to clinical research, authors should also state the animal model in the title.

To maximize reproducibility and potential for re-use of data, we encourage authors to follow the Animal Research: Reporting of In Vivo Experiments (ARRIVE) guidelines for all submissions describing laboratory-based animal research and to upload a completed <u>ARRIVE Guidelines Checklist</u> to be published as supporting information.

Non-human primates

Manuscripts describing research involving non-human primates must report details of husbandry and animal welfare in accordance with the recommendations of the Weatherall report, <u>*The use of non-human primates*</u> <u>*in research*</u>, including:

- Information about housing, feeding, and environmental enrichment.
- Steps taken to minimize suffering, including use of anesthesia and method of sacrifice, if appropriate.

Random source animals

Manuscripts describing studies that use random source (e.g. Class B dealer-sourced in the USA), shelter, or stray animals will be subject to additional scrutiny and may be rejected if sufficient ethical and scientific justification for the study design is lacking.

Unacceptable euthanasia methods and anesthetic agents

Manuscripts reporting use of a euthanasia method(s) classified as unacceptable by the <u>American Veterinary</u> <u>Medical Association</u> or use of an anesthesia method(s) that is widely prohibited (e.g., chloral hydrate, ether, chloroform) must include at the time of initial submission, scientific justification for use in the specific study design, as well as confirmation of approval for specific use from their animal research ethics committee. These manuscripts may be subject to additional ethics considerations prior to publication.

Human endpoints

Manuscripts reporting studies in which death of a regulated animal (vertebrate, cephalopod) is a likely outcome or a planned experimental endpoint, must comprehensively report details of study design, rationale for the approach, and methodology, including consideration of humane endpoints. This applies to research that involves, for instance, assessment of survival, toxicity, longevity, terminal disease, or high rates of incidental mortality.

Definition of a humane endpoint

A humane endpoint is a predefined experimental endpoint at which animals are euthanized when they display early markers associated with death or poor prognosis of quality of life, or specific signs of severe suffering or distress. Humane endpoints are used as an alternative to allowing such conditions to continue or progress to death following the experimental intervention ("death as an endpoint"), or only euthanizing animals at the end of an experiment. Before a study begins, researchers define the practical observations or measurements that will be used during the study to recognize a humane endpoint, based on anticipated clinical, physiological, and behavioral signs. <u>Please see the NC3Rs guidelines for more information</u>. Additional discussion of humane endpoints can be found in this article: Nuno H. Franco, Margarida Correia-Neves, I. Anna S. Olsson (2012) How "Humane" Is Your Endpoint? — Refining the Science-Driven Approach for Termination of Animal Studies of Chronic Infection. PLoS Pathog 8(1): e1002399 <u>doi.org/10.1371/journal.ppat.1002399</u>.

Full details of humane endpoints use must be reported for a study to be reproducible and for the results to be accurately interpreted.

For studies in which death of an animal is an outcome or a planned experimental endpoint, authors should include the following information in the Methods section of the manuscript:

• The specific criteria (i.e. humane endpoints) used to determine when animals should be euthanized.

- The duration of the experiment.
- The numbers of animals used, euthanized, and found dead (if any); the cause of death for all animals.
- How frequently animal health and behavior were monitored.
- All animal welfare considerations taken, including efforts to minimize suffering and distress, use of analgesics or anaesthetics, or special housing conditions.

If humane endpoints were not used, the manuscript should report:

- A scientific justification for the study design, including the reasons why humane endpoints could not be used, and discussion of alternatives that were considered.
- Whether the institutional animal ethics committee specifically reviewed and approved the anticipated mortality in the study design.

Observational and field studies

Methods sections for submissions reporting on any type of field study must include ethics statements that specify:

- Permits and approvals obtained for the work, including the full name of the authority that approved the study; if none were required, authors should explain why
- Whether the land accessed is privately owned or protected
- Whether any protected species were sampled
- Full details of animal husbandry, experimentation, and care/welfare, where relevant

Paleontology and archaeology research

Manuscripts reporting paleontology and archaeology research must include descriptions of methods and specimens in sufficient detail to allow the work to be reproduced. Data sets supporting statistical and phylogenetic analyses should be provided, preferably in a format that allows easy re-use. <u>Read the policy</u>.

Specimen numbers and complete repository information, including museum name and geographic location, are required for publication. Locality information should be provided in the manuscript as legally allowable, or a statement should be included giving details of the availability of such information to qualified researchers.

If permits were required for any aspect of the work, details should be given of all permits that were obtained, including the full name of the issuing authority. This should be accompanied by the following statement:

All necessary permits were obtained for the described study, which complied with all relevant regulations. If no permits were required, please include the following statement:

No permits were required for the described study, which complied with all relevant regulations. Manuscripts describing paleontology and archaeology research are subject to the following policies:

• Sharing of data and materials. Any specimen that is erected as a new species, described, or figured must be deposited in an accessible, permanent repository (i.e., public museum or similar institution). If study conclusions depend on specimens that do not fit these criteria, the article will be rejected under *PLOS ONE*'s data availability criterion.

• Ethics. *PLOS ONE* will not publish research on specimens that were obtained without necessary permission or were illegally exported.

Systematic reviews and meta-analyses

A systematic review paper, as defined by <u>The Cochrane Collaboration</u>, is a review of a clearly formulated question that uses explicit, systematic methods to identify, select, and critically appraise relevant research, and to collect and analyze data from the studies that are included in the review. These reviews differ substantially from narrative-based reviews or synthesis articles. Statistical methods (meta-analysis) may or may not be used to analyze and summarize the results of the included studies.

Reports of systematic reviews and meta-analyses should include a completed <u>PRISMA (Preferred Reporting</u> <u>Items for Systematic Reviews and Meta-Analyses)</u> checklist and flow diagram to accompany the main text. Blank templates are available here:

- Checklist: <u>PDF</u> or <u>Word document</u>
- Flow diagram: <u>PDF</u> or <u>Word document</u>

Authors must also state in their "Methods" section whether a protocol exists for their systematic review, and if so, provide a copy of the protocol as supporting information and provide the registry number in the abstract.

If your article is a systematic review or a meta-analysis you should:

- State this in your cover letter
- Select "Research Article" as your article type when submitting
- Include the PRISMA flow diagram as Fig 1 (required where applicable)
- Include the PRISMA checklist as supporting information

Meta-analysis of genetic association studies

Manuscripts reporting a meta-analysis of genetic association studies must report results of value to the field and should be reported according to the guidelines presented in <u>Systematic Reviews of Genetic Association</u> <u>Studies</u> by Sagoo *et al.*

On submission, authors will be asked to justify the rationale for the meta-analysis and how it contributes to the base of scientific knowledge in the light of previously published results. Authors will also be asked to complete a <u>checklist (DOCX)</u> outlining information about the justification for the study and the methodology employed. Meta-analyses that replicate published studies will be rejected if the authors do not provide adequate justification.

Personal data from third party sources

For all studies using personal data from internet-based and other third-party sources (e.g., social media, blogs, other internet sources, mobile phone companies), data must be collected and used according to company/website Terms and Conditions, with appropriate permissions. All data sources must be acknowledged clearly in the <u>Materials and Methods section</u>.

Read our policy on data availability.

In the Ethics Statement, authors should declare any potential risks to individuals or individual privacy, or affirm that in their assessment, the study posed no such risks. In addition, the following Ethics and Data Protection requirements must be met.

For interventional studies, which impact participants' experiences or data, the study design must have been prospectively approved by an Ethics Committee, and informed consent is required. The Ethics Committee may waive the requirement for approval and/or consent.

For observational studies in which personal experiences and accounts are not manipulated, consultation with an Ethics or Data Protection Committee is recommended. Additional requirements apply in the following circumstances:

- If information used could threaten personal privacy or damage the reputation of individuals whose data are used, an Ethics Committee should be consulted and informed consent obtained or specifically addressed.
- If authors accessed any personal identifying information, an Ethics or Data Protection Committee should oversee data anonymization. If data were anonymized and/or aggregated before access and analysis, informed consent is generally not required.

Note that Terms of Use contracts do not qualify as informed consent, even if they address the use of personal data for research.

See our reporting guidelines for human subjects research. Cell Lines

Authors reporting research using cell lines should state when and where they obtained the cells, giving the date and the name of the researcher, cell line repository, or commercial source (company) who provided the cells, as appropriate.

Authors must also include the following information for each cell line:

For *de novo* (new) cell lines, including those given to the researchers as a gift, authors must follow our policies for <u>human subjects research</u> or <u>animal research</u>, as appropriate. The ethics statement must include:

- Details of institutional review board or ethics committee approval; AND
- For human cells, confirmation of written informed consent from the donor, guardian, or next of kin

For established cell lines, the Methods section should include:

- A reference to the published article that first described the cell line; AND/OR
- The cell line repository or company the cell line was obtained from, the catalogue number, and whether the cell line was obtained directly from the repository/company or from another laboratory

Authors should check established cell lines using the <u>ICLAC Database of Cross-contaminated or</u> <u>Misidentified Cell Lines</u> to confirm they are not misidentified or contaminated. Cell line authentication is recommended – e.g., by karyotyping, isozyme analysis, or short tandem repeats (STR) analysis – and may be required during peer review or after publication.

Blots and Gels

Please review *PLOS ONE's* requirements for reporting blot and gel results and providing the underlying raw images.

Antibodies

Manuscripts reporting experiments using antibodies should include the following information:

- The name of each antibody, a description of whether it is monoclonal or polyclonal, and the host species.
- The commercial supplier or source laboratory.
- The catalogue or clone number and, if known, the batch number.
- The antigen(s) used to raise the antibody.
- For established antibodies, a stable public identifier from the Antibody Registry.

The manuscript should also report the following experimental details:

- The final antibody concentration or dilution.
- A reference to the validation study if the antibody was previously validated. If not, provide details of how the authors validated the antibody for the applications and species used.

We encourage authors to consider adding information on new validations to a publicly available database such as <u>Antibodypedia</u> or <u>CiteAb</u>.

Small and macromolecule crystal data

Manuscripts reporting new and unpublished three-dimensional structures must include sufficient supporting data and detailed descriptions of the methodologies used to allow the reproduction and validation of the structures. All novel structures must have been deposited in a community endorsed database prior to submission (please see our list of <u>recommended repositories</u>).

Small molecule single crystal data

Authors reporting X-Ray crystallographic structures of small organic, metal-organic, and inorganic molecules must deposit their data with the Cambridge Crystallographic Data Centre (CCDC), the Inorganic Crystal Structure Database (ICSD), or similar community databases providing a recognized validation functionality. Authors are also required to include the relevant structure reference numbers within the main text (e.g. the CCDC ID number), as well as the crystallographic information files (.cif format) as Supplementary Information, along with the checkCIF validation reports that can be obtained via the International Union of Crystallography (IUCr).

Macromolecular structures

Authors reporting novel macromolecular structures must have deposited their data prior to initial submission with the Worldwide Protein Data Bank (wwPDB), the Biological Magnetic Resonance Data Bank (BMRB), the Electron Microscopy Data Bank (EMDB), or other community databases providing a recognized validation functionality. Authors must include the structure reference numbers within the main text and submit as Supplementary Information the official validation reports from these databases.

Methods, software, databases, and tools

PLOS ONE will consider submissions that present new methods, software, databases, or tools as the primary focus of the manuscript if they meet the following criteria:

Utility

The tool must be of use to the community and must present a proven advantage over existing alternatives, where applicable. Recapitulation of existing methods, software, or databases is not useful and will not be considered for publication. Combining data and/or functionalities from other sources may be acceptable, but simpler instances (i.e. presenting a subset of an already existing database) may not be considered. For software, databases, and online tools, the long-term utility should also be discussed, as relevant. This discussion may include maintenance, the potential for future growth, and the stability of the hosting, as applicable.

Validation

Submissions presenting methods, software, databases, or tools must demonstrate that the new tool achieves its intended purpose. If similar options already exist, the submitted manuscript must demonstrate that the new tool is an improvement over existing options in some way. This requirement may be met by including a proof-of-principle experiment or analysis; if this is not possible, a discussion of the possible applications and some preliminary analysis may be sufficient.

Availability

If the manuscript's primary purpose is the description of new software or a new software package, this software must be open source, deposited in an appropriate archive, and conform to the <u>Open Source</u> <u>Definition</u>. If the manuscript mainly describes a database, this database must be open-access and hosted somewhere publicly accessible, and any software used to generate a database should also be open source. If relevant, databases should be open for appropriate deposition of additional data. Dependency on commercial software such as Mathematica and MATLAB does not preclude a paper from consideration, although complete open source solutions are preferred. In these cases, authors should provide a direct link to the deposited software or the database hosting site from within the paper. If the primary focus of a manuscript is the presentation of a new tool, such as a newly developed or modified questionnaire or scale, it should be openly available under a license no more restrictive than CC BY.

Software submissions

Manuscripts whose primary purpose is the description of new software must provide full details of the algorithms designed. Describe any dependencies on commercial products or operating system. Include details of the supplied test data and explain how to install and run the software. A brief description of enhancements made in the major releases of the software may also be given. Authors should provide a direct link to the deposited software from within the paper.

Database submissions

For descriptions of databases, provide details about how the data were curated, as well as plans for longterm database maintenance, growth, and stability. Authors should provide a direct link to the database hosting site from within the paper.

<u>Read the PLOS policy on sharing materials, software and code</u>. New taxon names

Zoological names

When publishing papers that describe a new zoological taxon name, PLOS aims to comply with the requirements of the <u>International Commission on Zoological Nomenclature (ICZN)</u>. Effective 1 January 2012, the ICZN considers an online-only publication to be legitimate if it meets the criteria of archiving and is registered in ZooBank, the ICZN's official registry.

For proper registration of a new zoological taxon, we require two specific statements to be included in your manuscript.

In the **Results** section, the globally unique identifier (GUID), currently in the form of a Life Science Identifier (LSID), should be listed under the new species name, for example:

Anochetus boltoni Fisher sp. nov. urn:lsid:zoobank.org:act:B6C072CF-1CA6-40C7-8396-534E91EF7FBB You will need to contact Zoobank to obtain a GUID (LSID). Please do this as early as possible to avoid delay of publication upon acceptance of your manuscript. It is your responsibility to provide us with this information so we can include it in the final published paper.

Please also insert the following text into the **Methods** section, in a sub-section to be called "Nomenclatural Acts":

The electronic edition of this article conforms to the requirements of the amended International Code of Zoological Nomenclature, and hence the new names contained herein are available under that Code from the electronic edition of this article. This published work and the nomenclatural acts it contains have been registered in ZooBank, the online registration system for the ICZN. The ZooBank LSIDs (Life Science Identifiers) can be resolved and the associated information viewed through any standard web browser by appending the LSID to the prefix "http://zoobank.org/". The LSID for this publication is: urn:lsid:zoobank.org:pub: XXXXXXX. The electronic edition of this work was published in a journal with an ISSN, and has been archived and is available from the following digital repositories: LOCKSS [author to insert any additional repositories].

All PLOS articles are deposited in <u>LOCKSS</u>. If your institute, or those of your co-authors, has its own repository, we recommend that you also deposit the published online article there and include the name in your article.

Botanical names

When publishing papers that describe a new botanical taxon, PLOS aims to comply with the requirements of the International Code of Nomenclature for algae, fungi, and plants (ICN). The following guidelines for publication in an online-only journal have been agreed such that any scientific botanical name published by us is considered effectively published under the rules of the Code. Please note that these guidelines differ from those for zoological nomenclature, and apply only to seed plants, ferns, and lycophytes.

Effective January 2012, the description or diagnosis of a new taxon can be in either Latin or English. This does not affect the requirements for scientific names, which are still to be Latin.

Also effective January 2012, the electronic PDF represents a published work according to the ICN for algae, fungi, and plants. Therefore the new names contained in the electronic publication of PLOS article are effectively published under that Code from the electronic edition alone, so there is no longer any need to provide printed copies.

Additional information describing recent changes to the Code can be found here.

For proper registration of the new taxon, we require two specific statements to be included in your manuscript.

In the **Results** section, the globally unique identifier (GUID), currently in the form of a Life Science Identifier (LSID), should be listed under the new species name, for example:

Solanum aspersum S.Knapp, sp. nov. [urn:lsid:ipni.org:names:77103633-1] Type: Colombia. Putumayo: vertiente oriental de la Cordillera, entre Sachamates y San Francisco de Sibundoy, 1600-1750 m, 30 Dec 1940, J. Cuatrecasas 11471 (holotype, COL; isotypes, F [F-1335119], US [US-1799731]). Journal staff will contact IPNI to obtain the GUID (LSID) after your manuscript is accepted for publication, and this information will then be added to the manuscript during the production phase

In the Methods section, include a sub-section called "Nomenclature" using the following wording:

The electronic version of this article in Portable Document Format (PDF) in a work with an ISSN or ISBN will represent a published work according to the International Code of Nomenclature for algae, fungi, and plants, and hence the new names contained in the electronic publication of a PLOS article are effectively published under that Code from the electronic edition alone, so there is no longer any need to provide printed copies.

In addition, new names contained in this work have been submitted to IPNI, from where they will be made available to the Global Names Index. The IPNI LSIDs can be resolved and the associated information viewed through any standard web browser by appending the LSID contained in this publication to the prefix http://ipni.org/. The online version of this work is archived and available from the following digital repositories: [INSERT NAMES OF DIGITAL REPOSITORIES WHERE ACCEPTED MANUSCRIPT WILL BE SUBMITTED (LOCKSS etc)].

All PLOS articles are deposited in <u>LOCKSS</u>. If your institute, or those of your co-authors, has its own repository, we recommend that you also deposit the published online article there and include the name in your article.

Fungal names

When publishing papers that describe a new botanical taxon, PLOS aims to comply with the requirements of the International Code of Nomenclature for algae, fungi, and plants (ICN). The following guidelines for publication in an online-only journal have been agreed such that any scientific botanical name published by us is considered effectively published under the rules of the Code. Please note that these guidelines differ from those for zoological nomenclature.

Effective January 2012, the description or diagnosis of a new taxon can be in either Latin or English. This does not affect the requirements for scientific names, which are still to be Latin.

Also effective January 2012, the electronic PDF represents a published work according to the ICN for algae, fungi, and plants. Therefore the new names contained in the electronic publication of PLOS article are effectively published under that Code from the electronic edition alone, so there is no longer any need to provide printed copies.

Additional information describing recent changes to the Code can be found here.

For proper registration of the new taxon, we require two specific statements to be included in your manuscript.

In the **Results** section, the globally unique identifier (GUID), currently in the form of a Life Science Identifier (LSID), should be listed under the new species name, for example:

Hymenogaster huthii. Stielow et al. 2010, sp. nov. [urn:lsid:indexfungorum.org:names:518624] You will need to contact either <u>Mycobank</u> or <u>Index Fungorum</u> to obtain the GUID (LSID). Please do this as early as possible to avoid delay of publication upon acceptance of your manuscript. It is your responsibility to provide us with this information so we can include it in the final published paper. Effective January 2013, all papers describing new fungal species must reference the identifier issued by a recognized repository in the protologue in order to be considered effectively published.

In the **Methods** section, include a sub-section called "Nomenclature" using the following wording. Note that this example is for taxon names submitted to MycoBank; please substitute appropriately if you have submitted to Index Fungorum using the

prefix http://www.indexfungorum.org/Names/NamesRecord.asp?RecordID=.

The electronic version of this article in Portable Document Format (PDF) in a work with an ISSN or ISBN will represent a published work according to the International Code of Nomenclature for algae, fungi, and plants, and hence the new names contained in the electronic publication of a PLOS article are effectively published under that Code from the electronic edition alone, so there is no longer any need to provide printed copies.

In addition, new names contained in this work have been submitted to MycoBank from where they will be made available to the Global Names Index. The unique MycoBank number can be resolved and the associated information viewed through any standard web browser by appending the MycoBank number contained in this publication to the prefix http://www.mycobank.org/MB/. The online version of this work is archived and available from the following digital repositories: [INSERT NAMES OF DIGITAL REPOSITORIES WHERE ACCEPTED MANUSCRIPT WILL BE SUBMITTED (LOCKSS etc)]. All PLOS articles are deposited in LOCKSS. If your institute, or those of your co-authors, has its own repository, we recommend that you also deposit the published online article there and include the name in your article.

Qualitative Research

Qualitative research studies use non-quantitative methods to address a defined research question that may not be accessible by quantitative methods, such as people's interpretations, experiences, and perspectives. The analysis methods are explicit, systematic, and reproducible, but the results do not involve numerical values or use statistics. Examples of qualitative data sources include, but are not limited to, interviews, text documents, audio/video recordings, and free-form answers to questionnaires and surveys.

Qualitative research studies should be reported in accordance to the <u>Consolidated criteria for reporting</u> <u>qualitative research (COREQ) checklist</u> or <u>Standards for reporting qualitative research (SRQR) checklist</u>. Further reporting guidelines can be found in the Equator Network's <u>Guidelines for reporting qualitative research</u>.

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Read the full instructions for <u>submitting to a journal with the Flat Fee Agreement</u>. If your corresponding author is not from a participating institution and requires assistance paying publishing fees, please consider <u>applying for a fee waiver</u> at submission.



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portal https://submission.wiley.com/journal/CPP. Should a manuscript proceed to the revision stage, authors will be directed to make revisions via the same submission portal. Authors may check the status of submission at any time by logging on to submission.wiley.com and clicking the "My Submissions" button. For technical help with the submission system, please review our FAQs or contact submissionhelp@wiley.com.

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CPP now offers Free Format submission for a simplified and streamlined submission process.

Before you submit, you will need:

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2. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Research Article: Substantial articles making a significant theoretical or empirical contribution (submissions should be limited to a maximum of 5,500 words excluding captions and references).

Comprehensive Review: Articles providing comprehensive reviews or meta-analyses with an emphasis on clinically relevant studies (review submissions have no word limit).

Measures Article: Articles reporting useful information and data about new or existing measures (assessment submissions should be limited to a maximum of 3,500 words).

Clinical Report: Shorter articles (a maximum of 2,000 words excluding captions and references) that typically contain interesting clinical material. These should use (validated) quantitative measures and add substantially to the literature (i.e. be innovative).

3. PREPARING THE SUBMISSION

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The manuscript should be submitted in separate files: main text file; figures.

File types

Submissions via the new Research Exchange portal can be uploaded either as a single document (containing the main text, tables and figures), or with figures and tables provided as separate files. Should your manuscript reach revision stage, figures and tables must be provided as separate files. The main manuscript file can be submitted in Microsoft Word (.doc or .docx) or LaTex (.tex) formats.

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Cover Letters and Conflict of Interest statements may be provided as separate files, included in the manuscript, or provided as free text in the submission system. A statement of funding (including grant numbers, if applicable) should be included in the "Acknowledgements" section of your manuscript.

The text file should be presented in the following order:

- 1. A short informative title containing the major key words. The title should not contain abbreviations (see Wiley's best practice SEO tips);
- 2. A short running title of less than 40 characters;
- 3. The full names of the authors;
- 4. The authors' complete institutional affiliations where the work was conducted (Institution Name, Country, Department Name, Institution City, and Post Code), with a footnote for an author's present address if different from where the work was conducted;
- 5. Conflict of Interest statement;
- 6. Acknowledgments;
- 7. Data Availability Statement
- 8. Abstract, Key Practitioner Message and 5-6 keywords;
- 9. Main text;
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