



**Exploring resilience amongst adults with Intellectual Disabilities and their care systems**

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**Word Count**

Thesis section	Main text (including tables and figures)	References	Total
Thesis overview	588	43	631
Literature review	8202	1998	10,200
Empirical paper	8726	1712	10,438
Appendices	5408	-	5408
<b>Total excluding references</b>	<b>22,924</b>		

### Thesis Overview

*“Resilience is the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and ‘bouncing back’ in the face of adversity. Across the life course, the experience of resilience will vary.”*

(Windle, 2011, p. 12).

The above definition depicts resilience as a response to adversity. Decades of research into the lives of people with Intellectual Disabilities (ID) demonstrate a disproportionately increased risk of adversity amongst this population. However, their resilience and the resilience of those who support them is currently under-researched. This thesis aimed to address this gap in knowledge by exploring resilience amongst people with ID and their caregiving systems. The citation above describes how influences within the individual, their life context and environment facilitate resilience. The life and environment milieu will inevitably comprise social and support networks. For example, family, friends, teachers and carers. When endeavouring to understand resilience, then, it seems important to consider the state and experiences of those around the individual, as well as the individual themselves. For example, by exploring psychological variables within the system. Two papers, a systematic review and an empirical study, form this thesis and are briefly outlined below.

The first paper is a systematic review of quantitative studies which provide interventions to direct care staff of those with ID, examining their impact on stress, burnout, resilience or wellbeing. Prior research has focussed more heavily on the negative psychological experiences of staff (stress and burnout), with a more limited focus on staff’s positive psychological variables such as wellbeing and resilience. Systematic search strategies enabled a review of 12 studies which were assessed for methodological rigour and which provided the

data for a narrative synthesis. Data showed some promise in the utility of mindfulness-based interventions in reducing staff stress and burnout. Conclusions were difficult to draw around wellbeing and resilience due to significant conceptual and measurement issues. Clinical and research implications are discussed, including the need for conceptual clarity and an increased focus on positive variables (wellbeing and resilience) in future ID staff research.

This is followed by the empirical paper which explores resilience amongst people with ID. The qualitative grounded theory study explored how Clinical Psychologists conceptualise resilience amongst people with ID, and how their conceptualisations are linked with practice. From the analysis of 12 interviews, a theoretical model was developed which explains how Clinical Psychologists think about and work with resilience when practicing with people with ID. Participants viewed resilience as a dynamic process of withstanding hardship and felt that hardships were magnified and unique for people with ID. Participants conceptualised resilience for people with ID as resulting from internal, environmental and macro-systemic influences. They rejected individualistic notions of resilience, instead seeing socio-political structures as crucial determinants. While all participants discussed their engagement at the individual and immediate systemic level, fewer described socio-political engagement to bolster resilience for people with ID. Numerous barriers to engagement at this level were evident. The findings add novel understandings of resilience in the lives of people with ID. The paper describes an ongoing study by Raye & Chadwick (2016) which explores resilience from the perspectives of those with lived experience of ID. The two empirical studies together will broaden understandings of resilience within this population. Research and clinical implications are discussed, which include understanding and addressing socio-political practice barriers for Clinical Psychologists and those employing them.

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Both papers have been prepared for submission to the Journal of Applied Research in Intellectual Disabilities (JARID).

### References

- Raye, E. & Chadwick, D. D. (2016). Resilience across the lifespan in adults with a learning disability: A systematic review. *Seattle Club Conference, Glasgow, 12–13*.
- Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology, 21*(02), 152-169.

**How effective are interventions targeting stress, burnout, wellbeing and resilience amongst those working with adults with Intellectual Disabilities? A systematic review.**

Prepared for submission to the Journal of Applied Research in Intellectual Disabilities (JARID).<sup>1</sup>

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<sup>1</sup> This manuscript was prepared in line with author guidelines for JARID (see Appendix 1). The word count for this journal is 7000 words. The American Psychological Association (6<sup>th</sup> edition) is the required style of referencing. The word count is exceeded, and tables and figures included in the main text, for examination purpose only.

## **Abstract**

### **Background**

Research suggests that staff who support people with Intellectual Disabilities (ID) can experience high levels of stress and burnout. The evidence base for positive psychological variables, such as wellbeing and resilience, is more limited. Studies have examined a range of interventions aiming to reduce negative staff experiences and/or promote positive psychological experiences. This review aimed to synthesise available studies.

### **Method**

This paper systematically reviewed 12 studies of mixed designs, to assess the efficacy of interventions for reducing staff stress or burnout, or improving wellbeing or resilience. Data were analysed using narrative synthesis and contextualised within standardised methodological quality appraisal.

### **Results**

Three studies were classified as 'limited' quality; four as 'adequate'; four as 'good'; one as 'strong'. There were inconsistent findings across stress, burnout, wellbeing and resilience in the utility of interventions undertaken. Overall, mindfulness-based intervention showed the most promise for reducing stress and burnout amongst staff, however available research is limited.

### **Conclusions**

Further research is needed to enhance knowledge about effective interventions which improve psychological experiences of staff working with adults with ID. Conceptual ambiguity and measurement limitations restricted the potential of the review, particularly with respect to

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wellbeing and resilience. Future studies should attend to construct validity, between-construct distinction, and an increased focus on wellbeing and resilience, in addition to stress and burnout.

### **Keywords**

Stress, burnout, resilience, wellbeing, staff, Intellectual Disabilities (ID)

## Introduction

Adults with Intellectual Disabilities (ID) experience intellectual and adaptive differences which have been present since childhood (British Psychological Society, 2015). Through associated challenges in functioning, many individuals require regular, ongoing support from informal (often family) or formal caregivers (McKenzie, 2016). This paper focuses on formal, paid, direct caregivers. These roles involve, but are not limited to, supporting skill development, personal care, activities and communication (Hatton et al., 1999a; Hastings, 2010). These roles might be undertaken in supported living/residential arrangements, within a person's own home, in inpatient facilities, day centres or other community provisions (Emerson et al., 2012).

Care work with individuals with ID can give rise to positive, meaningful staff experiences. For example, enhanced work-related quality of life, increased embracement of difference, greater acceptance, and reciprocal relational affection (Hastings & Horne, 2004). However, studies in this positively-oriented paradigm are rare. Conversely, emotional challenges associated with caring have been well-documented. Working conditions with insufficient support, long working hours, poor staffing levels and low pay, in a context where those needing support might express distress or unmet needs through behaviours which others find challenging, have been associated with negative staff outcomes (White, Edwards, & Townsend-White, 2006; Hewitt & Larson, 2007; Korsitas, Iacano, Carling-Jenkins & Chan, 2010). Further, associations between ID workers' psychological variables and negative staff outcomes have been found. For example, limited psychological acceptance or ascribing little value to the work being associated with increased stress and burnout (Noone & Hastings, 2011). Stress and burnout are two much-cited experiences amongst these employees (Devereux, Hastings & Noone, 2009; Skirrow & Hatton, 2007). Stress is characterised by

psychological and physical reactions (e.g. anxiety and fatigue) to stressors/stressful conditions (Rabkin & Struening, 1976; Demerouti, Bakker, Nachreiner & Schaufeli, 2001). One consequence of ongoing stress is burnout; an emotional experience typified by “exhaustion, depersonalisation, and reduced personal accomplishment” (Demerouti et al., 2001, p. 499). Levels of stress and burnout are reportedly between 25 and 32 per cent amongst staff working with those with ID (Hatton et al., 2001; Hastings, Horne & Mitchell, 2004).

Beyond these challenges for staff themselves, potential repercussions of stress/burnout include staff absenteeism, high staff turnover, unfavourable staff attitudes (i.e. unhelpful attributions of behaviour which challenges), reduced caregiver-client interaction, and restrictive/abusive practices (Hatton et al., 2001; Thompson & Rose, 2011; Rose, Horne, Rose & Hastings, 2004; Hastings & Remington, 1994; White, Holland, Marsland & Oakes, 2003). These findings have inevitable impacts for individuals being supported, and indicate a need for interventions targeting stress/burnout with a view to improving work-related experiences and ultimately the care experience of those with ID. Research suggests that targeting workers’ emotional experience (increasing non-judgemental acceptance and calm attention (mindfulness)) is associated with positive client outcomes (reduced physical restraints/medication for behaviours which challenge) (Singh et al., 2006; Singh et al., 2009).

The ID literature advises that positive and negative staff experiences are independent; assuming stress/burnout reduction is synonymous with positive staff experience is misguided (Lunsky, Hastings, Hensel, Arenovich & Dewa, 2014). Focusing on both positive and negative staff experiences is deemed necessary (Lunsky et al., 2014). In a systematic review, McCann et al. (2013) defined multidisciplinary *professional resilience* “as the ability to maintain personal and professional wellbeing in the face of ongoing work stress”, p. 61. As burnout is one form of stress (Demerouti et al., 2001), this quote pulls together four constructs; two in the

negative paradigm (stress and burnout) and two in the positive (resilience and wellbeing). These constructs were the focus of this review.

Resilience is “the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma” (Windle, 2011, p.12). Wellbeing is defined as “the balance point between an individual’s resource pool and the challenges faced” (Dodge, Daly, Huyton & Sanders, 2012, p. 230). However, these authors recognise that these are complex constructs, used ubiquitously yet varyingly, which have received contention over operationalisation. Mguni, Bacon and Brown (2012) elucidated that resilience and wellbeing are correlated yet distinct; it is possible to experience low resilience yet high wellbeing and vice versa. Though their research was not presented in a replicable way, their findings highlight potential utility in measuring resilience and wellbeing concurrently. Noone and Hastings (2009) reported that their intervention (based on Acceptance and Commitment Therapy, ACT) showed promise in bolstering ID staff resilience and wellbeing. However, this study was limited by a small sample size and the inference of resilience from changes in wellbeing and perceived work stressors.

A number of reviews have been undertaken in this area. Leoni, Corti, Cavagnola, Healy and Noone (2016) reviewed ACT interventions which targeted the reduction of stress/burnout and the improvement of wellbeing amongst ID staff. They concluded that these intervention studies showed promise for staff in terms of reducing stress and improving wellbeing, leading to an environment more functional to the care recipient. Authors concluded that future studies should incorporate larger samples, offer greater operational clarity on constructs, and conduct later follow-up assessments to assess longevity of outcomes (Leoni et al., 2016). The review usefully considered both positive and negative staff experiences as advised by Lunskey et al. (2014). Despite these advantages and important recommendations, the review focussed on only

one form of intervention, ACT. Further, this review was not undertaken systematically; methods, paper selection and analysis were not presented in the replicable format deemed optimal by Moher, Liberati, Tetzlaff, Altman and The PRISMA Group (2009).

Donchadha (2018) addressed the methodological weaknesses of the prior study, producing a replicable review which adhered to systematic review guidelines (Moher et al., 2009). Donchadha (2018) expanded inclusion criteria to incorporate any mindfulness-based intervention, not limited solely to ACT. Mindfulness was defined as, “awareness that emerges through paying attention on purpose, in the present moment, and non-judgementally to the unfolding of experience moment by moment” (Kabat-Zinn, 2003, p. 145). Of the eight studies reviewed for quality, three were appraised as ‘adequate’ and five as ‘weak’. Inconsistency was found in the impact of interventions upon stress. Distress, however, was consistently lower post-intervention and this was maintained at follow-up, demonstrating the promise of mindfulness-based interventions (Donchadha, 2018). The author concluded that a strength of mindfulness-based approaches was in promoting acceptance, rather than minimising or dismissing valid emotions. This review was consistent with Leoni et al. (2016) in stating limitations of small sample sizes and insufficient follow-up periods.

Despite relative strengths of the paper, Donchadha (2018) was again selective in eligible intervention modalities. Intervention options for staff which may warrant review extend beyond mindfulness. Further, the review did not distinguish between the experiences of staff working with children compared to those working with adults. It is feasible that working with adults comes with distinct challenges and rewards which warrant a more specific focus. For example, greater efforts to negotiate expectations with/for an adult with ID or being closer in age to them/having shared interests. Last, whilst Donchada (2018) reviewed positive mindful process outcomes (the Five Facet Mindfulness Questionnaire (Baer, Smith, Hopkins,

Krietemeyer & Toney, 2006), for example), broader positive variables such as staff wellbeing or resilience were not considered.

The current study addresses the limitations of earlier reviews by systematically reviewing the effectiveness of: *any* form of intervention for staff working with adults with ID, which focusses on stress, burnout, resilience and/or wellbeing. Not imposing a limit on intervention strategies permitted a potential opportunity for assessing comparative effectiveness. This systematic review held the potential to identify any discernible research and practical implications to improve the working lives of those working in adult ID services, and thus the lives of those with ID. Indeed, there is a legislative imperative for the health and wellbeing of staff to be prioritised in any workplace in Britain (Black, 2008), and more specifically in the healthcare context (Boorman, 2009). Both policy documents drive the importance of staff health and wellbeing at work upward and recognise that the staff experience has implications far beyond staff themselves; that it too influences those they work with. Within this policy context, the current review, with the aim of understanding more about how wellbeing and resilience can be improved, and stress/burnout can be reduced, is well-placed. Furthermore, policy which mandates a review and reduction of over-medication of people with ID (Stopping Over-Medication of People with a Learning Disability (STOMP), NHS England, 2018) is relevant here. Attending to the wellbeing of staff by offering interventions has been shown to be beneficial for staff themselves, and for reducing harmful practices impacting people with ID. For example, Singh et al. (2006) and Singh et al. (2009) found that improving staff experience with mindfulness-based intervention led to reduced use of both physical restraint and medication in response to behaviours which challenge staff/services. Expanding understanding about staff experience and how to improve this is crucial, then, to furthering improvements in the lives of people with ID.

## **Method**

This systematic review was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al., 2009) to ensure rigour. The paper outlines a systematic review of quantitative evidence. The review was registered in advance on the International Prospective Register of Systematic Reviews (PROSPERO) with registration number CRD42018087844.

### **Eligibility Criteria**

Studies which quantitatively explored the effectiveness of interventions for staff working with adults with ID were included. Studies of mixed experimental quantitative designs were eligible. Studies were included if they reported to measure stress, burnout, wellbeing or resilience. A limit was not imposed on outcome measures selected. To address limitations of earlier reviews, interventions of any kind were eligible. Reviews, study protocols, commentaries or discussion papers were ineligible. Staff had to work with adults with ID specifically; they were excluded if they supported only children, or those who had Autism Spectrum Disorder or learning difficulties (such as dyslexia) who did not also have ID. No other exclusions, such as mental health difficulties, were applied to the care group. Direct, paid staff participant groups were eligible (i.e. support workers, healthcare assistants and nurses) from any setting (NHS, independent, inpatient, community, third sector, charity or post-16 education provisions). As the staff group of interest was paid, direct caregivers, samples of unpaid/informal carers, family and other registered health professionals (e.g. psychology, occupational therapy, speech and language therapy and psychiatry) were not eligible. Eligible papers were written in English and published in peer-reviewed journals.

Table 1.

Search terms applied within PsychInfo

	<u>Key concept</u>	<u>Search terms</u>
Population	Paid, direct care staff ...  ... working with adults with Intellectual Disabilities	Staff OR nurse* OR "support worker*" OR "healthcare assistant*" OR "health care assistant*" OR "carer*" OR "care giver*" OR "care-giver*" OR "caregiver*" OR "nursing assistant*" OR "care provider*" OR "personnel" OR "personal assistant"  "Intellectual* disab*" OR "learning disab*" OR "mental* handicap*" OR "developmental* disorder*" OR "IDD" OR "intellectual* and developmental* disab*" OR "intellectual developmental disabilit*" OR "intellectual development disorder*" OR "mental* deficien*" OR "developmental* disab*" OR "intellectual development" OR "mental* retard*" OR "intellectual* impair*" OR "down syndrome" OR "fragile x" OR "Williams syndrome" OR "prader-willi"
Intervention	Any staff intervention strategy or format	Intervention* OR program* OR programme* OR course* OR training OR workshop* OR teaching OR group*
Outcome	Stress  Burnout  Resilience  Wellbeing	Stress  Burnout OR burn-out OR "burn out"  Resilien*  Wellbeing OR "well-being"

## Search Strategy

Free-text search terms were centred around the population, interventions and outcomes of interest. Key concepts under review were explored and terms agreed in detail amongst the authors. Table 1 depicts search terms applied within PsychInfo as an example. Remaining databases searched were Medline, CINAHL, Academic Search Complete and Scopus. Database thesauri and exploring previous reviews in this area further facilitated selection of search terms. Papers meeting inclusion criteria were hand-searched for any additional studies. The limiter function was applied to select studies published between 1990 and February 2018 inclusive.

## **Study Selection**

One reviewer, HW, screened all titles and abstracts of papers retrieved, excluding those which were not relevant. To improve robustness, a colleague of HW independently reviewed 10% of the screening with full agreement. Full texts of potentially relevant papers were then reviewed to assess eligibility. Exclusion at this stage was made with reasons noted. The same colleague of HW independently corroborated full-text eligibility assessments. Any discrepancies were discussed in detail until agreement was reached on the sample of papers to be included.

## **Assessment of Methodological Quality**

Assessments of quality and risk of bias were undertaken on papers retained, using the QualSyst quality appraisal tool for quantitative studies (Kmet, Lee & Cook, 2004; Appendix 2). QualSyst assesses 14 quality indicators of research papers. Reviewers generate scores based on 'yes', 'no', 'partially' or 'not applicable' answers. Papers were attributed an overall score (0-1) which indicated limited quality (less than 0.5), adequate quality (0.5-0.7), good quality (0.7-0.8), or strong quality (greater than 0.8). The tool allowed comparability of quality across studies. Quality appraisal was led by HW with independent inter-rater corroboration provided by a colleague. Disagreements were discussed directly until consensus reached. Quality appraisals were tabulated and are described narratively in the subsequent results section. No study was excluded based upon quality appraisal, rather quality assessment informed discussion of the evidence.

## **Data Extraction and Analysis**

A data extraction form was designed, comprising the headings within the ensuing data extraction tables (Table 2 and Table 4). Broadly the standardised form included publication details, study characteristics, participant demographics, methods and main statistical findings. The form was considered an iterative document, with fields open to revision throughout data extraction to ensure fields were appropriately saturated and all relevant data extracted. Papers were returned to if it later emerged that additional study characteristics/data were important to capture. Extracted data were tabulated to be supported by narrative interpretation. Meta-analysis was precluded by heterogeneity across studies.

## **Results**

### **Studies Identified and Included**

After duplicate removal, the search strategy identified 1263 unique records. After excluding a significant proportion of papers (1232) during screening, and 19 papers at the eligibility stage, 12 publications were retained for review (Gardner & Rose, 1994; Rose, Jones & Fletcher, 1998; Boumans & van den Berg, 2000; Innstrand, Espnes & Mykletun, 2004; Long, Collins, MacDonald, Johnston & Hardy, 2008; Noone & Hastings, 2010; Ingham, Riley, Nevin, Evans & Gair, 2013; McConachie, McKenzie, Morris & Walley, 2014; Singh et al., (2015); Singh, Lancioni, Karazsia & Myers (2016); Singh, Lancioni, Karazsia, Chan & Winton (2016); Singh et al., (2018). The process of paper identification through to inclusion is summarised in line with Moher et al. (2009), Figure 1.

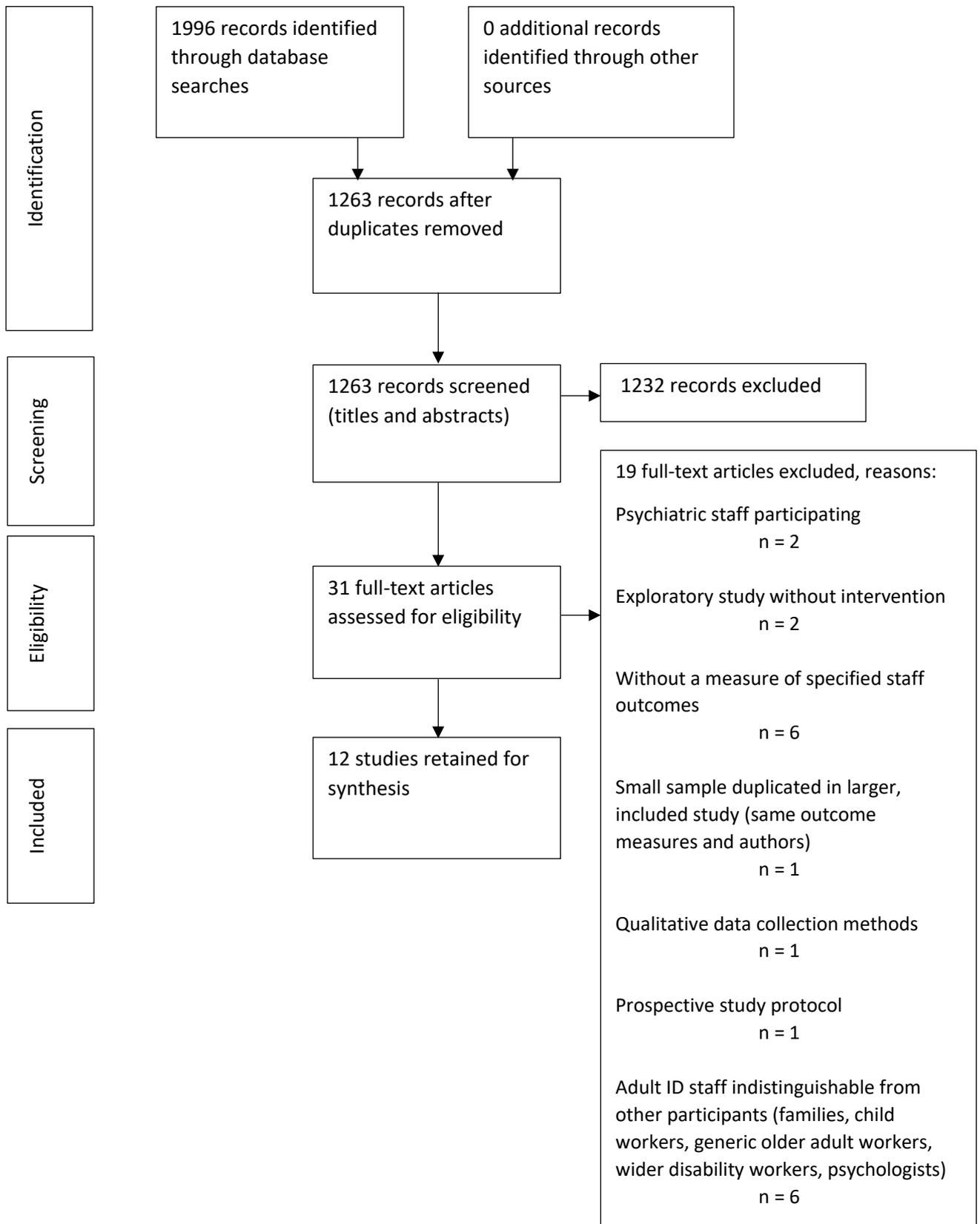


Figure 1. PRISMA flow of information diagram

### **Characteristics of Included Studies**

Study characteristics of the 12 individual studies are depicted in Table 2. Studies were published between 1994 (Gardner & Rose, 1994) and 2018 (Singh et al., 2018). All studies were conducted in developed countries: UK (6); USA (4); Netherlands (1); Norway (1). Study settings included day centres, inpatient and residential settings, and group homes. 1,052 participants took part in the studies. Gender split was not possible as two studies (Gardner & Rose, 1994; Rose et al., 1998) did not report this. In those that did report gender, there were substantially more females in all but one study (Singh et al., 2016a). Three studies did not report age (Gardner & Rose, 1994; Rose et al., 1998; Long et al., 2008). In those that did, there was a range of 19-69 years. There were five single-arm studies, three quasi-experimental studies, three Randomised Controlled Trials (RCTs), and one mixed between-within design. Nine studies implemented group-based workshops; two implemented organisational change initiatives (Boumans & van den Berg, 2000; Long et al., 2008); one provided individual and organisational level interventions (Innstrand et al., 2004). Where comparison groups were indicated by design, alternatives to 'no intervention' occurred in three studies; training on ID/person centred-planning (Ingham et al., 2013) and PBS training (Singh et al., 2016b; Singh et al., 2018). Intervention and control samples appeared adequately balanced except within Innstrand et al. (2004). Follow-up periods ranged from immediately post-intervention, to one year.

Table 2.

## Main study characteristics

<u>Author(s), (Year)</u>	<u>Geography</u>	<u>Setting(s)</u>	<u>Sample size, n:</u> <u>1. Baseline</u> <u>2. Retention</u> <u>at</u> <u>follow-up</u>	<u>Gender of those retained &amp; analysed, M:F</u>	<u>Mean age, years (range)</u>	<u>Study design</u>	<u>Objectives</u>	<u>Intervention details</u>	<u>Control condition (if applies)</u>	<u>Duration</u>	<u>N per group (interve- ntion: control)</u>
Gardner & Rose (1994)	UK	Local Authority (LA) day centre	1. 21 2. 14	Not stated	Not stated	Single-arm pre-post design	Assess & attempt to reduce stress	Group-based intervention; discussing stress/stress models; feedback on personal stress profile; support in stress-reducing goal setting/attainment	N/A	3 1-hour sessions	N/A
Rose et al. (1998)	UK	LA group homes	1. 32 2. 28	Not stated (7:25 at baseline)	Not stated	Randomised controlled trial (RCT): stress management condition versus control	Evaluate package to reduce demands/ constraints & increase supports	Group-based intervention; received results on team stress (context of Demand, Support Constraints Model); stress education & management; problem solving/goal setting	No intervention	1-day workshop; 1-hour monitoring session; 1- day follow-up session	14:18
Boumans & van den Berg (2000)	The Netherlands	Multi- setting; inpatient units, family units, day	1. 423 2. 257	52:205	33.4 (range not stated) at	Quasi- experimental pre-post design; job innovation	Evaluate effects of a job innovation model on	Innovating systemic caregiving (targeting personal caregiving, client- oriented approach, quality assurance, interdisciplinary	No intervention	1 year	222:201

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		centres, supervised housing			follow- up	intervention versus control	work/work perception	work, streamlined consultation structures, training)			
Innstrand et al. (2004)	Norway	Community residential care	1. Not stated 2. 112	Approximately 12:100	40 (21-65)	Quasi-experimental pre-post design; stress reducing initiatives versus control	To evaluate changes in stress, burnout (and job satisfaction)	Stress reducing interventions at individual level (stress-reducing solutions, exercise twice weekly for 2 months, seminars (e.g. motivation/self-care)) and organisational level (performance appraisals and working schedules improved)	No intervention	10 months	79:33
Long et al. (2008)	UK	Medium secure inpatient unit	1. Not stated 2. 12	Not stated	Not stated	Single-arm pre-post design	Determine effectiveness of procedures on staff morale	Organisational change; staff training, group & individual 'therapies', reflective groups, updated philosophy of client care, procedural changes, staff consultation	N/A	Not stated; an embedded change to working practices	N/A
Noone & Hastings (2010)	UK	Community residential service settings	1. Not stated 2. 34	10:24	41.71 (23-58)	Single-arm pre-post design	Review the case for acceptance and mindfulness upon work experiences	Group-based Promotion of Acceptance in Carers and Teachers (PACT) intervention, based on ACT	N/A	1-day PACT workshop; half day follow-up session several weeks following	N/A
Ingham et al. (2013)	UK	Inpatient service	1. Not stated 2. 58	23:35	39 (20-58)	Quasi-experimental pre-post	Examine a brief workshop	Group-based workshop of reflection, teaching and experiential exercises based	Group-based generic training on ID	1-day intensive workshops	37:21

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						design; resilience workshop versus generic training	aimed at developing resilience	on Cognitive Behaviour Therapy (CBT) and ACT	and person- centred planning		
McConachie et al. (2014)	UK	Independent care providers	1. Not stated 2. 120	31:89	43 (19- 69)	Mixed between- within participants design; acceptance and mindfulness versus control	Explore impact of acceptance & mindfulness on psychological distress/wellbe ing	Group-based ACT workshop to support stressful situation management – teaching, discussion, interactive exercises	No intervention	1-day workshop; half day refresher 6 weeks later	66:54
Singh et al. (2015)	USA	Community group homes	1. Not stated 2. 9	3:6	42 (23- 54)	Multiple baseline (single-arm) design	Evaluate effectiveness of mindfulness- based PBS in reducing stress	Group-based mindfulness; meditation, mindful observation of client behaviour, mindful responding	N/A	5 consecuti ve days	N/A
Singh et al. (2016a)	USA	Community groups homes	1. Not stated 2. 33	17:16	39 (19- 49)	Single-arm pre-post design	Evaluate effectiveness of mindfulness- based PBS for stress	As in Singh et al. (2015)	N/A	7 training days	N/A
Singh et al. (2016b)	USA	Large congregate care facility	1. Not stated 2. 75	24:51	Intervent ion: 43.05; control:	RCT; mindfulness- based positive behaviour	Asses effects of mindfulness- based PBS versus	As in Singh et al. (2015; 2016a)	PBS training (behavioural assessment, developing/ implementing	1-day; 5 days; 1- day (over 10 weeks)	37:38

					45.08 (23-62)	support versus control	treatment as usual upon carer outcomes		PBS plans plans; ethical considerations of behavioural work)		
Singh et al. (2018)	USA	Community group homes	1. 123 2. 116	Not stated (36:87 at baseline)	Intervention: 44.05; control: 42.84 (23-64)	RCT; mindfulness- based positive behaviour support (PBS) versus PBS	Assess effectiveness of mindfulness- based PBD versus PBS alone	As in Singh et al. (2016b)	As in Singh et al. (2016b)	As in Singh et al. (2016b)	59:57

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## Results of Quality Assessment

Applying QualSyst criteria (Kmet et al., 2004), three studies were appraised as ‘limited’ quality (Gardner & Rose, 1994; Innstrand et al., 2004; Ingham et al., 2013), four as ‘adequate’ quality (Rose et al., 1998; Boumans & van den Berg, 2000; Long et al., 2008; Singh et al., 2015), four as ‘good’ quality (McConachie et al., 2014; Noone & Hastings, 2010; Singh et al., 2016b; Singh et al., 2018), and one as ‘strong’ quality (Singh et al., 2016b). Table 3 depicts how each paper scored against 14 quality criteria and the overall quality rating. Criteria and scoring detail is available (Appendix 2; Kmet et al., 2004).

Overall, studies had clear, well defined research objectives and appropriate designs. The most common methodological limitations were omitting: procedures of randomisation and blinding (in studies where this was possible); data on estimates of variance (e.g. confidence intervals); and strategies for controlling for confounders. With regards the latter, several studies failed to report between-group baseline comparability. Table 3 shows that four studies did not fully describe methods of analyses, and four did not sufficiently describe results (for example, omitting means or offering partial outcome data). Results did not support the conclusions within six studies. For instance, one study concluded overall “success” when the intervention with one group had a detrimental impact upon the control group (Innstrand et al., 2004). Due to these limitations, main findings should be interpreted with some caution.

Table 4 offers detail on outcome measures within studies. Tools employed were generally well described and robust psychometric properties outlined (criteria 8, Table 3). However, methodological quality concerns were raised regarding construct validity. Measurement problems included:

- One study purported to be measuring stress, yet measured depression and anxiety (Gardner & Rose, 1994).

- One study was not clear whether they were measuring stress or wellbeing; they measured depression and anxiety, and demands/supports (Rose et al., 1998).
- The General Health Questionnaire (GHQ-12) was used to measure stress in one study (McConachie et al., 2014), yet wellbeing in another (Noone & Hastings, 2010).
- Resilience or burnout (not clear which) was measured with the Emotional Responses to Aggressive Challenging Behaviour questionnaire (Ingham et al., 2013).
- Inferring that resilience had increased, from measuring burnout (Ingham et al., 2013).

Table 3.

Quality appraisal ratings

<u>Study</u>	<u>Quality criteria</u>														<u>Summary score (quality rating)</u>
	1. Objectives described	2. Design evident/apt	3. Sampling described/apt	4. Participants described	5. Randomised & described	6. Researcher blinding	7. Participant blinding	8. Measures robust/described	9. Sample size appropriate	10. Analysis described & apt	11. Reports variance estimates	12. Controls for confounding	13. Sufficiently details results	14. Results support conclusion	
Gardner & Rose (1994)	1	1	1	0	X	X	X	1	1	0	0	0	0	1	0.27 (limited)
Rose et al. (1998)	1	2	1	1	1	0	0	1	1	2	1	2	2	2	0.60 (adequate)
Boumans & van den Berg (2000)	2	2	2	1	0	0	0	2	2	2	0	1	2	1	0.60 (adequate)
Innstrand et al. (2004)	2	1	1	1	0	0	0	1	2	1	0	1	1	1	0.43 (limited)
Long et al. (2008)	2	2	1	0	X	X	X	1	1	2	0	0	2	2	0.59 (adequate)
Noone & Hastings (2010)	1	2	0	2	X	X	X	2	2	2	2	1	2	1	0.77 (good)
Ingham et al. (2013)	1	1	1	2	0	0	0	0	2	1	1	0	1	1	0.39 (limited)
McConachie et al. (2014)	2	2	1	2	2	0	0	2	2	2	1	2	1	1	0.71 (good)
Singh et al. (2015)	2	1	2	2	X	X	X	2	1	1	0	0	2	2	0.68 (adequate)
Singh et al. (2016a)	2	2	1	2	X	X	X	2	2	2	1	0	2	2	0.81 (strong)
Singh et al. (2016b)	2	2	2	2	2	0	0	2	1	2	1	2	2	2	0.78 (good)
Singh et al. (2018)	2	1	1	2	1	0	0	2	2	2	1	2	2	2	0.71 (good)

Note. 'Yes' scored 2, 'Partially' scored 1, 'No' scored 0, 'Not applicable' (X) not scored & excluded from summary score. See Appendix 2 for further scoring detail.

## **Main Findings**

Table 4 details outcome measures employed, timepoints they were implemented, analyses undertaken, and main findings across 12 studies. Data are here discussed narratively under the four psychological constructs of interest.

### **Effectiveness of interventions upon stress.**

Nine studies considered stress as an outcome measure of intervention effectiveness. Mixed findings were evident. Two studies reported non-significant pre-post differences in stress (Gardner & Rose, 1994; Noone & Hastings, 2010). The first was a stress psychoeducation intervention, measuring stress with the Thoughts and Feelings Index (TFI); the second an ACT intervention, measuring stress with the Staff Stressor Questionnaire (SSQ).

Two studies had mixed findings across different measures of stress. In an ACT intervention, McConachie et al. (2014) found significant improvements across intervention and control groups on the GHQ-12, however found increases in stress means (measured by the SSQ) across both groups. Using the TFI and demands/supports as possible stress measures, Rose et al. (1998) found that anxiety significantly reduced in the Job Demands Constraints intervention group and supports significantly increased; respectively these were non-significantly and significantly different to controls. However, there were no differences in the depression TFI subscale or demands measure.

Five studies found reductions in stress. Singh et al. (2015; 2016a; 2016b; 2018) found mindfulness-based interventions to be associated with significant reductions in stress, using the Perceived Stress Scale-10 (PSS-10) as an outcome measure. The two most recent studies reported large effect sizes. Applying a range of stress-reducing interventions (individual level

and organisational level), Innstrand et al. (2004) found significant reductions in stress amongst the intervention group, however the control group worsened.

### **Effectiveness of interventions upon burnout.**

Five studies measured the efficacy of their intervention in reducing staff burnout and findings were again varied. Two studies found non-significant pre-post differences in burnout (Ingham et al., 2013; Boumans & van den Berg, 2000). Both measured burnout with the Maslach Burnout Inventory (MBI); the first was a CBT/ACT intervention and the second an innovation in the care system.

One study had mixed findings across different domains of burnout as measured by the General Burnout Inventory (GBI): exhaustion, cynicism and professional self-efficacy (Innstrand et al., 2004). The group receiving a range of interventions (see Table 3), had significantly reduced burnout compared to controls, however non-significant between-group differences were found in cynicism and professional self-efficacy.

Two studies found their interventions to be effective in reducing burnout. Using the MBI as a measure of the impact of a care innovation package (see Table 3), Long et al. (2008) found significant reductions in emotional exhaustion and depersonalisation, with increased personal accomplishment. Using a burnout subscale of the Professional Quality of Life scale (ProQOL), Singh et al. (2018) found the mindfulness-based intervention condition to be effective in reducing burnout with a large effect size (see Table 4).

### **Effectiveness of interventions upon wellbeing.**

Three studies focussed on wellbeing as a potential intervention outcome and findings across studies were inconclusive and mixed. Rose et al. (1998) were unclear on whether scales employed related to stress or wellbeing; both were noted and discriminating the two measures

according to construct was not discernible. As described under the stress subheading above, stress/wellbeing findings were mixed. One study (McConachie et al., 2014) found that an ACT intervention led to non-significant changes in wellbeing as measured by the Warwick Edinburgh Mental Wellbeing Scale (WEMWBS). A third study (Noone & Hastings, 2010) found their ACT intervention to be associated with significant improvements in wellbeing, as measured by the GHQ-12.

#### **Effectiveness of interventions upon resilience.**

Only one study mentioned resilience as an outcome of focus. Ingham et al. (2013) found that their resilience workshop, combining CBT and ACT, had a significant reduction on the negative Emotional Responses to Aggressive Challenging Behaviour (ERACB) scores, with a medium-large effect size. Significance was found in the intervention group alone. The authors did not note how the ERACB relates to resilience.

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Table 4.

Outcome measurement, analyses and main findings

<u>Study</u>	<u>Methods of assessing stress, burnout, resilience or wellbeing</u>	<u>Measurement timepoints</u>	<u>Relevant analyses</u>	<u>Relevant findings/data available</u>
Gardner & Rose (1994)	<b>Stress</b> - (by measuring one effect of stress; 'strain') - Thoughts and Feelings Index (TFI) (depression and anxiety scales) (Fletcher, Jones & Turner, 1991)	Baseline; 1-week post-intervention; 8-month follow-up	Comparison of means	Non-Significant (NS) changes on both scales at one week & 8 months. Pre-intervention means (anxiety 10.94; depression 8.50). 8-month follow-up means (anxiety 10.21; depression 8.35).
Rose et al. (1998)	<b>Stress/wellbeing</b> (not clear on focus) – TFI and 'demands & supports' (Rose, 1993)	Baseline; 4-5 months post-intervention	MANOVA	Anxiety significantly reduced in intervention group (mean pre-intervention = 11.00; post-intervention = 9.69; $F(1,27) = 4.82$ ; $p < .05$ ); not in control group (mean pre-intervention = 9.75; mean post-intervention = 9.87; $F(1,27) = 3.19$ , $p > .05$ ). NS between-group differences on anxiety ( $F(1,27) = 3.19$ , $p = .08$ ). NS depression findings; no data offered. 'Supports' significantly increased in intervention group (mean pre-intervention = 3.28; mean post-intervention = 3.50; $F(1,27) = 5.28$ , $p < .05$ ); not in control group (mean pre-intervention = 3.74; mean post-intervention = 3.70; $F = 0.21(1,27)$ , ns); between-group differences significant ( $F(1,27) = 4.06$ , $p < 0.05$ ); effect size ( $q^2 = .131$ ) (medium). NS 'demands' findings; no data offered.
Boumans & van den Berg (2000)	<b>Burnout</b> – Maslach Burnout Inventory (MBI) (Maslach, Jackson, Leiter, Schaufeli & Schwab., 1986)	Baseline; 1-year post-baseline	ANCOVA	NS between-group findings on three burnout domains at follow-up: Emotional exhaustion (intervention mean = 14.83; control mean = 15.38, $F = 1.71$ , $p = 0.192$ ); Depersonalization (intervention mean = 4.52; control mean = 4.82, $F = 0.22$ , $p = 0.64$ ); Personal accomplishment (intervention mean = 35.16; control mean = 34.51, $F = 2.49$ , $p = 0.116$ ). NS within-group differences across three domains ( $p < 0.001$ ).
Innstrand et al. (2004)	<b>Stress</b> – specifically devised 23 item stress measure. <b>Burnout</b> – General Burnout Questionnaire (GBI) (Schaufeli, Leiter & Kalimo, 1995)	Baseline; 10 months post-baseline	ANCOVA	Significant between-group differences in stress ( $F = 10.49$ , $p < 0.05$ ). Burnout: significant between-group differences in exhaustion ( $F = 4.99$ , $p < 0.05$ ); NS differences across groups in cynicism and professional self-efficacy. Control group score direction was opposite/negative to intervention group, indicating increased stress & burnout.

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Long et al. (2008)	<b>Burnout</b> – MBI (Maslach et al., 1986)	Prior to and 6 months following procedural change	Wilcoxon Signed Ranks Test	Subscales: significant reductions in emotional exhaustion ( $z = -2.80, p < 0.01$ ) & depersonalisation ( $z = -2.19, p < 0.05$ ). Significant increase personal accomplishment ( $z = -2.046, p < 0.05$ ).
Noone & Hastings (2010)	<b>Wellbeing</b> – General Health Questionnaire (GHQ-12). <b>Stress</b> – Staff Stressor Questionnaire (SSQ) (Hatton et al., 1999b)	Beginning of session 1; end of session 2	Related samples t tests	NS reduction in SSQ scores ( $t(33)=1.24, p=0.225; d=0.12$ ). Significant reduction in GHQ-12 scores with a medium effect ( $t(33)=2.45, p=0.02; d=0.48$ ).
Ingham et al. (2013)	<b>Burnout</b> – MBI. “ <b>To improve resilience through mediating against burnout</b> ” (pp. 219) - Emotional Responses to Aggressive Challenging Behaviour questionnaire (ERACB, Mitchell & Hastings, 1998).	Pre and immediately post workshop	Independent samples t tests	Intervention group: significant reduction in negative ERACB (pre mean = 27.76, post mean = 22.90, $t = 7.94, df = 36, p < 0.001$ ), with medium-large effect size (0.7). NS pre/post change on MBI. Control group: NS pre/post changes on ERACB and MBI.
McConachie et al. (2014)	<b>Wellbeing</b> – Warwick Edinburgh Mental Wellbeing Scale (WEMWBS, Tennant et al., 2007). <b>Stress</b> – GHQ-12 & SSQ	Baseline; at 6-week refresher; 6 weeks later	Mixed ANOVAS	NS interaction effect (time * condition) for WEMWBS scores ( $F = 2.747, p = 0.72$ ). Significant interaction effect (time * condition) for GHQ-12 scores ( $F = 8.061, p = 0.001$ ), with medium to large effect. Significant reductions both groups; control group less pronounced. Inferential SSQ statistics omitted. Intervention means increased from 66.5 (time 1) to 67.34 (time 3); control means from 66.37 (time 1) to 68.21 (time 2).
Singh et al. (2015)	<b>Stress</b> - Perceived Stress Scale-10 (PSS-10, Cohen et al. 1983)	Pre-baseline; baseline; last day of group	Repeated measures ANOVA	Continual downward trend; PSS-10 scores reduced significantly across timepoints ( $F(2, 16)=170.26, p < 0.001 (\eta^2=.96)$ ).
Singh et al. (2016a)	<b>Stress</b> - PSS-10	Pre-intervention; intervention-end; 40-week follow-up	Repeated measures ANOVA	Continual downward trend; stress scores significantly reduced across timepoints ( $F(2,64) = 417.56, p < 0.001, \eta^2 = 0.93$ ). Means at 3 timepoints: 29.88, 22.00, 14.15 respectively.
Singh et al. (2016b)	<b>Stress</b> - PSS-10	Baseline; 40-week follow-up	Mixed-model ANOVA	Significant interaction effect (time * condition) ( $F(1,73) = 73.70, p < 0.001 (\eta^2 D 0.50)$ ). Between group differences NS at baseline (effect size, $d = 0.36$ ); significant at follow-up (large effect size, $d = 2.78$ )

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Singh et al. (2018)	<b>Stress</b> – PSS-10. <b>Burnout</b> – Burnout subscale of Professional Quality of Life (ProQOL) (Stamm, 2010)	Baseline; 40-week follow-up	T tests and multiple linear regression	The effect of time ( $R^2$ change = 0.41, $\beta$ = -0.64) and effect of condition after controlling for time ( $R^2$ change = 0.16, $\beta$ = -0.41) were significant ( $p < 0.001$ ) on PSS-10. Effect of time ( $R^2$ change = 0.42, $\beta$ = -0.65) and effect of condition after controlling for time ( $R^2$ change = 0.18, $\beta$ = -0.43) were significant ( $p < 0.001$ ) on ProQOL:burnout. Both conditions effective in reducing burnout and stress; intervention condition explained a further 10-18% of the variance in data. NS between-group differences in pre-intervention means (stress & burnout). Significant ( $p < 0.001$ ) between-group differences in pre-intervention means, with large effect sizes (stress, $d = 2.48$ ; burnout, $d = 2.34$ )
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## Discussion

This systematic review examined 12 studies which assessed the effectiveness of interventions upon stress, burnout, wellbeing or resilience amongst direct care workers of adults with ID. Previous reviews have focussed on ACT (Leoni et al., 2016) and mindfulness-based interventions (Donchadha, 2018). This review extends beyond prior reviews by: addressing methodological limitations, being inclusive of any staff-based intervention (beyond ACT and mindfulness), focussing on staff stress, burnout, wellbeing and resilience, and looking specifically at interventions for those working with adults with ID.

The narrative synthesis explored changes which occurred within the psychological constructs of interest (stress, burnout, wellbeing and resilience) as a result of intervention. Turning first to stress, where mixed and inconsistent findings were evident. When the results of studies were non-significant, construct invalidity may offer an explanation. For example, Gardner and Rose (1994) and Rose et al. (1998) inferred stress from measures of anxiety and depression by using the TFI. In contrast, the TFI has been used to measure wellbeing in other studies (Jenkins, Rose & Lovell, 1991).

Of the five studies demonstrating intervention efficacy for stress reduction, four implemented group-based mindfulness training (Singh et al., 2015; Singh et al., 2016a; Singh et al., 2016b; Singh et al., 2018) and one was a multi-layered intervention including exercise, self-care skills, and modifying work patterns (Innstrand et al., 2004). Systematic reviews in mental health and physical health have also demonstrated the efficacy of mindfulness-based interventions in reducing staff stress (Rudaz, Twohigh, Ong & Levin, 2017; Van Der Riet, Levett-Jones & Aquino-Russell, 2018). In the recent review by Donchadha (2018), the promise of this approach was highlighted for staff in ID settings specifically. However, compared to reviews of over 20 papers in other fields, ID staff research is limited, and further research is

needed. Importantly, one study in the current review did not conduct a follow up beyond the immediate end of intervention (Singh et al., 2015) and three studies conducted 40-week follow-ups (Singh et al., 2016a; Singh et al., 2016b; Singh et al., 2018). Future research could encompass longer-term follow-ups to assess the longevity of beneficial effects. It was challenging to compare Innstrand et al. (2004) against available literature due to the specific, multifaceted nature of the intervention.

The four mindfulness-based studies were appraised as adequate, good or strong quality, and used specific stress measures, which enhanced credibility of the findings. However, the multi-componential study (Innstrand et al., 2004) was appraised as limited quality. The authors used a 23-item stress measure devised specifically for the study, which they did not detail, and the study was categorised a “success” despite the control group becoming significantly more stressed. Further, the intervention incorporated multiple elements and it was not possible to determine what proportion of stress reduction was attributable to each. The findings suggestive of efficacy are therefore contentious.

Two studies reported the efficacy of intervention in reducing staff burnout. Using the MBI, Long et al. (2008) found reductions across the three burnout subscales after implementing systemic care innovations. The focus on organisational determinants of burnout in addition to an employee focus is commendable (Morse, Salyers, Rollins, Monroe-DeVita & Pfahler, 2012). However, deducing what specifically was useful in reducing burnout was not possible. For example, staff undertook individual and group-based ‘therapies’, however specific elements of the approach were not described. Further, the setting, a female medium secure inpatient unit, makes conclusions difficult to generalise. Mindfulness was found to be an effective approach for reducing burnout (Singh et al., 2018). With a large effect size and strong quality rating, this offers some support for the utility of mindfulness in addressing burnout. A

prior systematic review evidenced the efficacy of mindfulness-based interventions for burnout in healthcare staff and teachers in wider fields (Janssen, Heerkens, Kuijer, Van Der Heijden & Engels, 2018). With respect to ID staff, only one other study was identified which explores mindfulness (in the context of ACT) in relation to burnout, amongst psychologists, social workers, teachers and direct care staff. Bethay, Wilson, Schnetzer, Nassar and Bordierir (2013) found that amongst participants who reported significant distress at baseline, those receiving ACT reported greater reductions in the believability of burnout-related thoughts than control group counterparts. However, mindfulness research specifically targeting ID workers' burnout is limited, suggesting a need for further research.

Inconsistent findings were evident in studies targeting burnout. Where studies yielded inconclusive or non-significant results, specific burnout measures with adequate psychometric properties, such as the MBI, were used (Ingham et al., 2013; Boumans & van den Berg, 2000; Innstrand et al., 2004). The lack of significant effects are here explored. The one-day CBT/ACT intervention was potentially too time-limited to address the complex construct of burnout (Ingham et al., 2013). It has been recommended that interventions targeting burnout should be delivered over time rather than in standalone sessions (Morse et al., 2012). The multi-componential systemic innovation did not lead to reductions in burnout (Boumans & van den Berg, 2000). This may be explained by the non-comparable between-group baselines, and/or control group contamination effects, described by the authors. Nevertheless, this study is strengthened by focussing on organisational and individual influences upon burnout, rather than solely on one technique, or on employees only (Morse et al., 2012).

Of papers that focussed on wellbeing, one study did not discern if their measures related to stress or wellbeing (Rose et al., 1998). The study yielded inconclusive results, however the loose relating of wellbeing to chosen measures meant any conclusions would have

been contentious. One study employed a specific wellbeing tool (WEMWBS), however the ACT intervention did not lead to significant changes in wellbeing (McConachie et al., 2014). This could be explained by the intervention being too brief (1.5 days). However, a systematic review of mental health staff also found insufficient data to support mindfulness or ACT in enhancing wellbeing, explained partially by varied participant adherence to the strategies taught (Rudaz et al., 2017). Noone and Hastings (2010) found significant increases in wellbeing following the ACT intervention. However, they utilised the GHQ-12 as a measure of wellbeing; other reviewed papers used this measure to capture stress. Further, the follow-up was ‘several’ weeks later which precludes assessment of the longevity of beneficial effects.

There were clear conceptual and measurement issues with wellbeing, which prevented the review question from being fully answered. This fits with wellbeing being described elsewhere as a complex, contested construct (Dodge et al., 2012). What is clear is that wellbeing cannot be inferred from reduction of stress or burnout (Lunsky et al., 2014). In summary, the limited data available is insufficient to support the utility of interventions for wellbeing amongst staff working with adults with ID. Wellbeing is a key priority for care staff such as those working in the NHS (Boorman, 2009), both for their own experience and experiences of those they support. More research is therefore required to increase understanding about staff wellbeing, its measurement and how to foster it. Such research should provide clear conceptual definitions and ensure construct validity.

One paper explored resilience as an outcome. From their CBT/ACT intervention, Ingham et al. (2013) concluded efficacy in fostering resilience amongst staff. However, resilience was inferred from the ‘Emotional Responses to Aggressive Challenging Behaviour’ scale. There was no definition of resilience provided, nor an explanation of how the scale related to resilience. Using this scale, staff rate the frequency of their negative emotions (e.g.

disgusted, nervous and helpless) when those they support display behaviours which challenge. Whilst reducing frequency of difficult feelings may be favourable, the authors did not account for how this related to resilience. Resilience is described as adapting to, managing or ‘bouncing back’ from stress/adversity (Windle, 2011); not the avoidance of difficult feelings. Further, Windle (2011) cautions against viewing the absence of distress as synonymous with resilience, and in fact suggests that distress plus ‘bouncing back’ may be the uppermost example of resilience.

Conceptual confusion regarding resilience is evident elsewhere. A review of ‘resilience training’ packages delivered within a range of workplaces found that only six of 14 studies employed a resilience measure (Robertson, Cooper, Sarkar & Curran, 2015). Comparable to the current findings, these studies had measurement issues such as not providing a definition of resilience, not measuring the same construct they were targeting, and inferring resilience from other psychological constructs.

One subconstruct of resilience is stress/adversity. Given that ID staff face adversities of long working hours, insufficient training, imbalances of effort-reward, and retendering processes meaning organisational uncertainty (Lin et al., 2009; Health & Social Care Act, 2012), resilience seems pertinent. However, the limited data available does not yet provide support for the utility of staff interventions to foster resilience. In fact, the measurement limitations identified precluded this part of the review question from being answered fully. Broadening the currently limited resilience research should therefore prioritise conceptual clarity, construct validity, and homogenising how resilience is understood and assessed (Robertson et al., 2015).

### **Strengths, Limitations and Research Implications**

The review was strengthened by following PRISMA guidelines for systematic reviews (Moher et al., 2009). A second strength was the inclusivity of any staff-based intervention, which provided an opportunity to review studies beyond ACT (Leoni et al., 2016) and mindfulness (Donchadha, 2018). Last, the review included positive (wellbeing and resilience) as well as a negative (stress and burnout) outcome foci; important as increasing one is not tantamount to reducing the other (Lunksy et al., 2014; Windle, 2011). Nonetheless, this review should be considered in the context of some important limitations, both of papers reviewed and the review itself.

As described earlier in the discussion and results sections, key limitations of reviewed studies centre around conceptual/measurement issues; construct validity, using terms interchangeably and making inferences about changes in one construct from observed changes in another. In addition, only four papers focussed on positive psychological constructs, and those focusing on wellbeing and resilience did not provide conceptual definitions. Conceptual/measurement limitations, which were also described by Leoni et al. (2016), reduced the potential of the review, as clear conclusions could not be drawn, particularly from studies focussing on wellbeing and resilience. The limitations highlight that future researchers should: be aware of conceptual complexity, pay attention to construct validity, avoid using terms discussed herein interchangeably, avoid making inferences about one construct through changes in another, and pay attention to positive psychological variables (e.g. wellbeing and resilience).

Additional limitations included papers lacking sufficient intervention detail, with descriptions of “therapies” not provided, for example (Long et al., 2008). Further, quality appraisal accentuated that future research examining staff interventions should undertake and

report on randomisation and double-blinding processes, as well as controlling for confounders and providing estimates of variance within results.

It is noted that one paper was excluded due to sample ambiguity. Brooker et al. (2013) described a mindfulness intervention for ‘disability workers’, which may have added something further to the review. However, it was unclear what specific disabilities this incorporated. HW tried however was unable to make contact with the authors for clarification (Appendix 3). Further, this review focussed on intervention effectiveness and quantitative evidence. It was noted during the review process that qualitative evidence was available which explored experiences of ID staff undertaking workplace interventions. This was a potential missed opportunity. Future reviews might synthesise qualitative papers, which may provide helpful information for designing staff interventions. Finally, heterogeneity in constructs of focus, measurement, design and analyses precluded meta-analysis, which could have provided a more robust analysis than the narrative analysis discussed. A more standardised research agenda which homogenises measurement of stress, burnout, wellbeing and resilience may facilitate future meta-analyses.

### **Clinical Implications**

The most promising interventions were mindfulness-based techniques including mindfulness-based PBS, for reducing staff stress and burnout. These studies were appraised as adequate to strong quality and offered detailed, transparent, ‘off-the-rack’ staff interventions. These strategies could easily and usefully be applied to clinical practice. Singh et al. (2015; 2016a) also detail the impact of these interventions upon service user variables, for example the frequency with which physical restraint and medication is utilised. Therefore, these readily translatable staff interventions might also be advantageous for the lives of those with ID.

One study observed the control group worsen in stress while their counterparts received intervention, which they attributed to ‘resentful demoralisation’ or continued stress in the context of no change to the sources (Innstrand et al., 2004). This is crucial for both research and practice. Those delivering staff interventions must commit due care, attention and ethical principles to control groups. Control groups could receive a different intervention as offered by Singh et al. (2018), or the same intervention (yet subsequent to the trial) should the intervention be effective.

## **Conclusions**

Interventions aiming to reduce stress or burnout, or increase wellbeing or resilience, in staff working with those with ID have centred around mindfulness, CBT and ACT, as well as stress psychoeducation, reflection and consultation groups, and organisational changes such as embedding client-centred approaches and updated working schedules. This systematic review examined 12 staff-based intervention studies and highlighted that mindfulness-based interventions show some promise in reducing stress and burnout for staff working with adults with ID, though further research is necessitated. Conclusions were restricted due to significant conceptual and measurement issues, particularly with respect to wellbeing and resilience. Future research could attend to the conceptual complexity which has been described and focus on staff psychological experiences in the positive paradigm (i.e. wellbeing and resilience) as well as in the negative (i.e. stress and burnout) (Lunsky et al., 2014). Reducing staff stress and burnout, and bolstering their wellbeing and resilience, is crucial not only for staff but indirectly has positive implications for those with ID being supported.

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**How do perceptions of resilience amongst people with Intellectual Disabilities influence clinical practice? A grounded theory of the perspectives of Clinical Psychologists.**

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<sup>2</sup> This manuscript was prepared in line with author guidelines for JARID (see Appendix 1). The word count for this journal is 7000 words. The American Psychological Association (6<sup>th</sup> edition) is the required style of referencing. The word count is exceeded, and tables and figures included in the main text, for examination purpose only.

## **Abstract**

### **Background**

Resilience is described as a process of adapting to adversity. Despite overwhelming evidence suggesting that people with Intellectual Disabilities (ID) experience a heightened risk of adversity, resilience amongst this population is currently under-researched.

### **Method**

Utilising grounded theory, this study aimed to develop a theoretical model explaining how resilience is conceptualised and worked with amongst one group of professionals, Clinical Psychologists. Semi-structured interviews were undertaken with 12 Clinical Psychologists working with adults with ID. Data collection and analysis were undertaken from a social constructivist standpoint, guided by Charmaz (2014).

### **Results**

Clinical Psychologists viewed resilience amongst this population as a complex interplay of intrapersonal, systemic/interpersonal, and macro socio-political influences. Adversities were perceived as unique and heightened, and resilience (a dynamic process of withstanding hardship) was considered an exceptionally relevant construct for this population, though often latent. Clinical Psychologists experienced reverence for the resilience demonstrated by people with ID. Participants undertook multifaceted approaches, engaging at many levels, to foster resilience in the lives of people with ID. They highlighted the importance of engaging socio-politically to bolster resilience, however shared practical barriers to this work.

**Conclusions**

The findings have important implications for the understanding and lives of people with ID, the practices of Clinical Psychologists and their employing organisations.

**Keywords**

Resilience, Intellectual Disabilities, Clinical Psychology practice, grounded theory

## Introduction

Intellectual disability (ID) is defined as “a significant impairment in intellectual functioning and significant impairment in adaptive behaviour (social functioning), with each of these impairments beginning prior to adulthood” (British Psychological Society (BPS), 2015, p. 2). People with ID are estimated to represent approximately 2% of the population (Krahn, Hammond & Turner, 2006).

When compared to those without ID, people with ID are disproportionately at risk of poor health and healthcare, poverty, reduced employment and educational opportunities, abuse, stigma, homelessness, social exclusion and a lack of friendships. (Emerson & Baines, 2011; Walsh, Kerr & van Schrojenstein Lantman-De Valk, 2003; Sobsey, 1994; Werner, Corrigan, Ditchman & Sokol, 2012; Hebblethwaite, Hames, Donkin, Colman & Forsyth, 2007; Landman, 2014; Disability Rights Commission, 2006). These findings highlight that people with ID frequently do not have their human rights upheld (chiefly humanity, equality, dignity, respect and autonomy) (Joint Committee on Human Rights (JCHR), 2008). Instead, their rights to live ‘a life like any other’ are too often breached (JCHR, 2008). This account of risk and inequality demonstrates that people with ID are more likely than those without to experience a range of hardships. Experience of, and ability to manage, such challenges is influenced by cognitive and psychosocial functioning such as problem-solving abilities, executive functioning, self-esteem and social supports (van den Hout, Arntz & Merckelbach, 2000; Walsh et al., 2003), as well as social factors such as being held in poor esteem by society (Beail, 2016).

Risk-focussed studies, as those above, highlight inequalities facing those with ID and enable researchers and clinicians to better understand their needs. However, support practices shaped solely by risk knowledge can be detrimental for people with ID. Sellars (2011) suggests that a risk/vulnerability emphasis in the care context of those with ID can lead to over-

protective, risk-averse practices. This inadvertently denies people opportunities to take life chances and learn via experience as others do, whilst limiting choice and self-determination, resulting in restricted lives (Sellars, 2011). Further, emphasising risk/vulnerability may perpetuate prevailing deficit-focussed models of ID. These ideas indicate a need for complementary research in the positive paradigm; moving beyond restrictive frameworks which view people with ID as vulnerable and narrowly defined by deficit (Goodley, 2000).

In other fields, one positive psychological process which has attracted much attention is resilience. Though the operationalisation of resilience has been one of contention and debate (Fletcher & Sarkar, 2013), a definition via concept analysis by Windle (2011) is now increasingly cited in the literature and is adopted in the current study:

*“Resilience is the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and ‘bouncing back’ in the face of adversity. Across the life course, the experience of resilience will vary.”* (p. 12).

Other operationalisations do exist, however, and resilience has a complex conceptual history. Definitions are usually two-pronged, broadly comprising adversity and positive adaptation to adversity. For example, Kaplan, Turner, Norman and Stillson (1996, p. 158) define resilience as “the capacity to maintain competent functioning in the face of major life stressors” and others have defined resilience as “the capacity for successful adaptation, positive functioning or competence ... despite high-risk status, chronic stress, or following prolonged or severe trauma. (Egeland, Carlson, & Sroufe, 1993, p. 517). Early resilience studies focussed on identifying individual characteristics which helped young people to thrive despite living in chronic, adverse circumstances such as poverty and institutionalisation (Garmezy, 1991; Rutter, 1990; Werner & Smith, 1992). The internal characteristics identified as resilience-

promoting included an easy temperament and high self-esteem. Such research tended to view resilience as dispositional, trait-based and, as such, people could be described as ‘resilient’ or not. Later research shifted away from internal, trait-focussed understandings, to exploring resilience as a dynamic process which places greater emphasis on systems, environment and culture (Luthar, Cicchetti, & Becker, 2000). Comparable to Windle (2011), who highlighted the life and environment milieu in the process of resilience, Ungar (2011) emphasises the social and physical ecologies around people in the process of experiencing resilience. Ungar (2011), however, prioritises the influence of context first, before turning to the person’s internal resources and locus of control. Ungar, Ghazinour and Richter (2013) have related resilience to Bronfenbrenner’s Ecosystems Theory (1979), purporting that this link has progressed resilience understandings from a micro focus on individual traits, to a “multisystemic understanding of person-environment reciprocal processes.” (p. 348).

Resilience is considered a risk modifier, and policy and practice innovation can be guided by resilience research implications (Seccombe, 2002; Luthar, Sawyer & Brown, 2006). Other fields such as adult mental health, child development, and physical health have attracted many resilience studies which have now undergone systematic reviews (Hu, Zhang & Wang, 2015; Lou, Taylor & Di Folco, 2018, in press; Eicher, Matza, Dubey & White, 2015). However, resilience amongst people with ID remains an under-researched topic. This is despite literature suggesting that focussing on resilience amongst this population could improve their lived experience. For example, Goodley (2005) suggests that a resilience focus could assist society in appreciating the contributions/capabilities of people with ID which, in turn, could support their self-advocacy and empowerment. Further, fostering positive, strengths-based perspectives could safeguard the human rights of people with ID, as harmful and negative publicly held views (e.g. passive community membership) can be challenged (JCHR, 2008). Additionally, if risk and resilience are ‘two sides of the same coin’ (Luthar et al., 2006) then

greater understanding about resilience amongst people with ID may reduce aversive clinical risk practices described by Sellars (2011). Last, understanding resilience amongst those with ID seems pertinent when risk of adversity, a requisite subconstruct of resilience (Windle, 2011), is reliably increased.

Research has explored resilience amongst children with ID, and resilience amongst family members of people with ID. In a sample of 115 children with ID and 106 children without, Gilmore, Campbell and Shochet (2013) found that aspects of the ‘resilience profiles’ of children with ID were similar their ‘typically developing’ counterparts. Of the assets purported to underpin resilience, non-significant between-group findings were found in optimism, self-efficacy and emotional recovery time. Where children with ID differed from those without was: reduced tolerance, goal-setting and planning assets, along with higher emotional sensitivity. Within external resilience resources, children with ID reported greater supports in school than their counterparts, yet lower community participation/inclusion.

Turning to resilience amongst family members of those with ID. A narrative review resulted in a resilience model which comprised “search for meaning, a sense of control, and the maintenance of valued identities” in the face of adversity (Grant, Ramcharan & Flynn, 2007, p. 571). These were considered conducive to resilience in a context of optimum “material, social, cultural and political influences” and negotiating useful boundaries (within the family and at the interface with support services) (Grant et al., 2007, p. 572). Whilst these studies contribute to understanding resilience amongst children and families, research has so far overlooked the conceptualisation and experience of resilience amongst adults with ID.

Luthar et al. (2006) recommend that resilience research must consider salient factors in the life-context of specific populations. As children with ID grow older, they will likely encounter different or greater risk/adversity, therefore resilience may become more pertinent.

Windle (2011) concluded that resilience varies across life trajectories, hence a need to research resilience amongst adults with ID. At the time of writing, no published studies were identified which conceptualise the construct of resilience specifically in adults with ID or explore its relevance to clinical practice. The current study aimed to go some way in addressing this gap.

### **The Current Study**

When little is known about a topic, qualitative research has utility in facilitating early understandings (Donalek & Soldwisch, 2004). Preliminary qualitative research to understand resilience amongst adults with ID should valuably focus on the perspectives of those with lived experience. Providentially, Raye and Chadwick (2016) (ongoing) are conducting such research, utilising mixed methods to develop a model of resilience amongst adults with ID, from the perspectives of adults with ID and their caregivers.

The current study aimed to complement the work of Raye and Chadwick (2016) by exploring an additional perspective of resilience amongst adults with ID, that of Clinical Psychologists. Clinical Psychologists were selected as the professional focus as they are likely to work with people who have experienced high levels of adversity. Further, a commitment to supporting people at multiple levels to ameliorate distress from adversity, and maximise more favourable outcomes, potentially inclusive of resilience, is inherent in the professional ethos (British Psychological Society, 2010). This participant group also allowed the exploration of how views about resilience may be related to clinical practice.

The study aimed to develop an explanatory theory of how Clinical Psychologists conceptualise resilience amongst adults with ID, and how understandings influence clinical practice. In line with Emerson (2013), the study offered potential indications for future resilience research and interventions which foster resilience in the lives of people with ID.

## **Method**

This study employed grounded theory methodology which has utility where there is a paucity of pre-existing knowledge and where research intends to conceptualise the meaning of phenomena, with a view to theory development (Bryant & Charmaz, 2007). This approach was therefore suitable to the study aims. Grounded theory is inductive and resultant theory is grounded in participants' lived experience and accounts. The study followed social constructivist grounded theory guidelines, with epistemological underpinnings of symbolic interactionism (Charmaz, 2014). Participant accounts and researcher interpretations were both viewed as socially constructed; together they co-constructed knowledge and ideas (Charmaz, 2014).

### **Sampling and Participants**

Prior to contacting services and potential participants, ethical approval was granted by the University of Liverpool Health and Life Sciences Committee on Research Ethics (Appendix 4). The Health Research Authority granted permission to conduct this research with employees across multiple National Health Service (NHS) trusts (Appendix 5).

Study advertisements (Appendix 6) were emailed to Lead Psychologists in four participating NHS trusts for distribution to their colleagues. The first author presented the study at a local Special Interest Group for Clinical Psychologists working in ID services, and the advertisement was distributed to this group's emailing list.

Initially five participants were recruited and interviewed purposively based on the following criteria: English speaking NHS Clinical Psychologists working with adults (>18 years) with ID for a minimum of 12 months. As grounded theory is iterative (Charmaz, 2014), sampling evolved throughout the study. Emerging ideas from analysing initial interviews

directed subsequent sampling strategies (theoretical sampling). A questionnaire inquiring about role information (e.g. NHS banding and theoretical orientation) supported theoretical sampling (Appendix 7). Simultaneous data collection, analysis and theoretical sampling continued until theoretical saturation was confirmed on analysing interview 12. That is, when new data failed to enhance the categories, model or overall structure (Charmaz, 2014).

Twelve Clinical Psychologists were interviewed from four NHS trusts in England. Participants were aged between 30 and 48. Their number of years qualified and working in ID services ranged between one and 24 years. Participants' NHS pay scale bandings ranged between 7 and 8c. Further participant information is provided in Table 1. However, the participant information reported is limited to protect participant anonymity. To preserve participants' anonymity, pseudonyms are assigned and employing organisations and Clinical Psychology training courses attended are withheld.

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Table 1.

Participant characteristics

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<b><u>Pseudonym</u></b>	<b><u>Gender</u></b>	<b><u>Service setting</u></b>	<b><u>Theoretical/therapeutic orientation(s)</u></b>
Stephanie	Female	Community	CBT (traditional/third wave), systemic, behavioural, CAT
Michelle	Female	Community	Narrative, CBT
Caroline	Female	Community & inpatient	DBT, behavioural, narrative, CBT
Rachel	Female	Community	Systemic, CBT, CAT
Sophie	Female	Inpatient	Behavioural, systemic
Hazel	Female	Community	CAT, behavioural, CBT
Maggie	Female	Community	Systemic, narrative
Jane	Female	Community	Systemic, PBS
Connie	Female	Community	CAT, systemic
Alison	Female	Inpatient	Narrative, CAT
Abigail	Female	Community	CAT, CBT, systemic, mentalisation-based

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*Note.* DBT = Dialectical Behaviour Therapy. CBT = Cognitive Behaviour Therapy. CAT = Cognitive Analytic Therapy. PBS = Positive Behaviour Support.

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## **Data Collection**

Participants met with the first author privately at their usual NHS base, at a time of their choosing. The researcher encouraged reading/re-reading of the participant information sheet (Appendix 8) and invited additional questions. Participants signed an informed consent form prior to interview (Appendix 9). Interviews were guided by an interview schedule (Appendix 10) which asked questions such as “What do you understand the term resilience to mean?”, “What do you perceive to be the factors that facilitate resilience in people with ID?”, and “Do your ideas and experiences of resilience in this group have implications for your practice?” Semi-structured interviews were utilised due to their inherent flexibility. Interview schedules remained open and evolved as a result of emerging ideas from preceding interviews (Charmaz, 2014). Interviews lasted between 46 and 65 minutes. They were audio recorded using a dictaphone, and transcribed verbatim for subsequent analysis.

## **Involvement of Experts by Experience**

University-based Experts by Experience provided consultation in refining the study direction. They directed the researchers to a local charity run with and for people with ID. Charity members are providing consultation on disseminating easy-read study findings, accessible for people with ID.

## **Researcher Reflexivity**

Co-creation of knowledge between participants and researchers requires researcher reflexivity (Charmaz, 2014). I, the first author, am a Clinical Psychology Trainee with a clinical interest in working with people with ID. My work prior to doctoral training was in ID services and I chose my final clinical placement to be in the specialty. My interest was in part due to embracing and celebrating diversity, whilst having a passion to understand and confront social

injustice and discrimination. I had experienced people with ID as demonstrating resilience in the face of significant, multiple adversities and was often shocked by people's ability to carry on in complex, hostile circumstances. I view ID from a social constructionist standpoint, whereby societal norms of success (academia, employment and monetary worth) 'impair' or disable people by exclusion. I remained attuned to these beliefs throughout, and the potential impact upon data collection and analysis. My background was discussed critically in supervision as both an opportunity and a potential limiter. Memo writing encouraged bidirectional reflection on how the research and I affected one another. Memo writing preserved a true grounding of theory in data, rather than a priori expectations shaping the analytic process. A more in-depth reflexive statement is available in Appendix 11; a memo example in Appendix 12.

## **Analysis**

Analysis was undertaken by the first author with remaining authors engaging in reliability checks and critical reflection in supervision. Analytic steps outlined by Charmaz (2014) were observed, outlined below. Appendix 13 demonstrates initial and focussed codes subsumed within conceptual categories, while Appendix 14 shows how one transcript excerpt was coded at different levels.

**Initial coding.** This involved labelling short segments of interview transcripts with emerging analytic ideas, whilst remaining 'close to' the data. Coding at this stage was primarily labelled to reflect action (Charmaz, 2014).

**Focussing coding.** This analysed, made sense of, and compared initial codes. Focussed codes both comprised many initial codes, and involved coding initial codes (Charmaz, 2014). Focussed codes were more abstract/theoretical than initial codes and supported the subsequent conceptual construction of categories (Charmaz, 2014).

**Conceptual category development.** This process followed and theorised focussed codes which best represented what was happening in the data. Conceptual categories give form to ideas, processes, relationships and patterns amongst codes (Charmaz, 2014). Conceptual categories were illuminated through the constant comparison of codes with codes, through memo writing and diagramming.

**Memos.** Memo writing encouraged enhanced, ongoing engagement with data and analytic ideas. Constructing sequential memos-to-self captured insights, comparisons, connections, questions and directions to follow in subsequent data collection/analysis (Charmaz, 2014). Memo writing (Appendix 12) helped raise focussed codes to conceptual categories.

**Diagramming.** Diagramming visually mapped participants' individual analytic stories, patterns and relationships (Charmaz, 2014). A diagramming example is available in Appendix 15. Diagrams were compared across participants and salient components, best representing what was occurring in the collective data set, retained. The final theoretical model (Figure 1, below) is, in part, the result of accruing and revising prominent segments of individual diagrams to represent the whole data set.

**Saturation/theory development check.** Iterative recruitment, data collection and analysis continued until theoretical saturation was indicated at interview 11. Interview 12 was then utilised as both an interview and a 'theory development check'. The interview first revealed that established focussed codes and categories accounted for the participant's narrative. A tentative visual model (Figure 1) was then shared with the participant, who felt that it explicated her conceptualisations and experiences.

## Results

Figure 1 below depicts the theoretical model which explains how Clinical Psychologists conceptualise resilience amongst people with ID and how their understandings relate to clinical practice. The theoretical model took the form of three core conceptual categories (demonstrated with the thicker shape outline, Figure 1):

- Making sense of resilience
- Clinician experiences
- Clinical practice & engagement to bolster resilience

Below, conceptual categories are discussed in turn, with reference to focussed codes underpinning them, and trajectories within/between them, and evidenced by participant quotations.

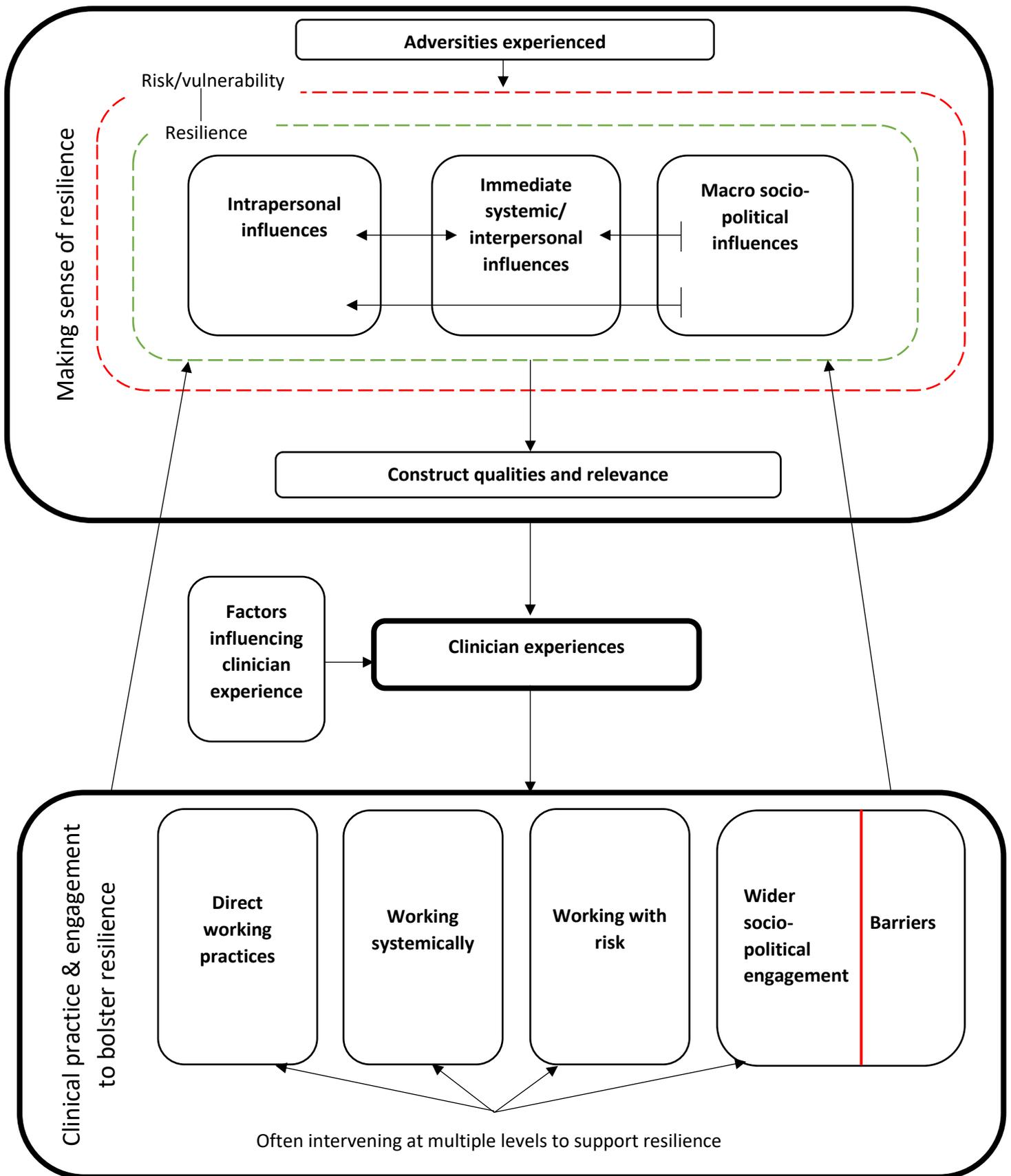


Figure 1. Theoretical model explaining how conceptualisations of resilience relate to practice

### **Making Sense of Resilience**

**Adversities experienced.** Participants understood resilience as a response to hardship; adversity was requisite for experiencing resilience. Adversities facing people with ID were considered magnified and unique. For example, participants suggested that people with ID had a greater likelihood of poor health, abuse and marginalisation than those without ID. There was consensus in a significant multiplicity and cumulativeness of adversity:

*“Everything that you could imagine that could be thrown at somebody, had ... as well as having a learning disability she had physical health issues, diabetes, visual difficulties, a horrendous childhood, erm sexual abuse, physical abuse, emotional abuse.”* (Hazel).

As suggested by Hazel, many participants perceived having ID as a unique adversity which could prompt the resilience process. ID being experienced as an adversity was attributed to entrenched societal stigma from birth:

*“The literature talks about shame or guilt and its not the ‘perfect child’. To be born into a world where a label you’re given is perceived so negatively by society ... how do you go through life with that?”* (Michelle).

Further unique adversities were incremental daily challenges encountered due to cognitive and social differences. Adversities did not have to be major traumatic life events, rather they included pervasive day-to-day difficulties in understanding:

*“It makes everything just that bit harder. From watching the soaps ... knowing what people are talking about on the phone, understanding what your letters are about.”* (Caroline).

**Influencers of resilience.** Participants perceived people with ID as able to experience resilience in the face of adversity, with suitable influences from a range of sources. The centre of ‘Making sense of resilience’ (Figure 1) comprises three inextricable areas of influence; intrapersonal, immediate systemic/interpersonal, and macro socio-political. These interlinked influences buffer against the impact of adversity and help people with ID to manage. Salient ‘intrapersonal influences’ (within-person assets) were: emotional understanding and regulation skills, self-esteem, drive/persistence toward new experiences, autonomy in goal setting, bravery, hope and humour. Alison’s example of the emotional asset was:

*“He’s been able to think to himself “Oh I’m feeling angry about this, what do I know helps me? ... listening to music might help me or taking myself out the situation might ... I’ll seek out support.””*

Intrapersonal assets were not viewed solely as individuals’ innate responsibilities/traits, rather they were buttressed by systemic and macro socio-political influences. ‘Immediate systemic/interpersonal influences’ were characteristics or relating styles within the caregiving system. Ways of being supported in these contexts considered conducive to resilience included ‘having person-centred care’, ‘having breadth of life experience’, ‘needing closeness with others’, ‘having ordinary relational lives’, and ‘systemic resilience’. These excerpts explicate these influences in turn:

*“people have taken the time to learn about the person, consider their needs and get an understanding ... even if its just ... the best way to communicate with them” (Michelle).*

*“Letting people make mistakes ... go through difficult things ... fully experience emotions and know that they’ll be ok at the end of it.” (Rachel).*

*“someone to talk things through with so things don’t spiral too quickly ... having somebody whether its friends or just a support worker you can trust and feel safe with.”*

(Rachel).

*“they were throwing parties at New Year’s Eve ... friends sleeping in the house in sleeping bags ... basically the same as what other people would do but their friends had learning disabilities.”* (Sophie).

*“well-led, well-managed, well-supported systems ... staff know if they’re doing well or not, they feel that it’s a rewarding thing ... if there are any problems they can raise them ... those things make for a resilient system.”* (Jane).

‘Macro socio-political influences’ encapsulated the role of governmental expenditure, policy/legislation, cultural attitudes/behaviour, and representation in society/media upon resilience. All participants expressed dissatisfaction and disdain about processes at this level, and negative impacts upon the lives and resilience of people with ID and their systems. For example:

*“Because they’re doing well the package is cut ... that kind of constantly looking for ways of saving money has a direct influence ... even just kind of the tendering process, where agencies have to tender for the business every 4 years ... there’s always another hurdle for them.”* (Maggie).

*“There is an implicit model of deficit around learning disability and we often see people in terms of lack ... there’s not a culture that necessarily celebrates good role modelling and good stories.”* (Connie).

The unidirectional arrows from this domain demonstrate how participants agreed on the influence of wider contextual pressures upon intrapersonal and interpersonal influences. However, there was no evidence of person or the system resources influencing macro factors.

Resources within three levels of influence were implicitly bipolar constructs. High levels, or positive examples, of these resources were viewed as conducive to resilience; low/poor levels were aligned with risk/vulnerability (hence the risk and resilience pathways (broken lines, Figure 1)). Participants' accounts at two levels (intrapersonal and immediate systemic/interpersonal) were primarily framed positively, where they had tangible evidence of these resources. Conversely, at the macro level, accounts were framed in the negative pole, suggesting what they perceived to be deficient here.

**Construct qualities and relevance.** Participants defined resilience as coping with, withstanding, or getting through hardships, though *“not necessarily unscathed”* (Michelle). All participants saw resilience as an *“ever-changing construct”* (Stephanie) and felt that people dynamically move between the risk/vulnerability and resilience pathways (broken lines, Figure 1.) depending on availability of influences, within the three levels of influence, at any timepoint. Interestingly, resilience appeared to be a latent construct in participants' understanding and practice, *“although resilience threads through so much of the work and people's lives, I'm interested that the word is rarely used.”* (Caroline).

Participants suggested that resilience has a higher relevance for people with ID compared to those without as *“they're statistically people who come across more adversity in their lives ... therefore would be more likely to display resilience”* (Michelle). Further, participants felt that the weighting of what is needed for resilience is different in this population, *“You're not just looking at resilience for the person its resilience very much in the system which is probably quite different to somebody without [ID]”* (Hazel). In addition to the

interplay of resilience influencers described above, this highlights the interdependent nature of resilience experienced by participants; the construct is not solely intrinsic, but also systemically and societally bound.

### **Clinician experiences**

All participants gave emotion-laden accounts expressing reverence for resilience amongst people with ID. For example, *“I’m always surprised ... in awe of what people kind of go through ... There’s a lot that I learn from people that I work with in terms of how they get through things.”* (Maggie). And, *“I get to meet people who have demonstrated the most extraordinary resilience ... people who have got extraordinary powers of survival”* (Jane). Admiration-based accounts were influenced by empathy and making personal comparisons; participants felt that under similar adverse circumstances they would not manage. For example, *“you just think, I’m not sure if I was in your shoes, having all that thrown at me, I don’t know if I’d have been able to deal with it, go on.”* (Hazel).

Five participants expressed changes in views and recognition of resilience amongst people with ID over time; four of these changes were favourable from participants’ perspectives. Caroline described increased recognition of resilience with career progression, *“I thought I was helping people who were more vulnerable, less able to cope .. As I’ve carried on throughout my career I’ve recognised that the amount that people with LD have and do cope with is astonishing.”* The key experience influencing increased recognition over time was accruing evidence of resilience: *“that cumulative effect of seeing people be resilient so frequently in my work leads to seeing people as more resilient.”* (Stephanie).

Alison interestingly described a revelatory shift in how she viewed resilience as a construct, perceiving it as less intrinsic than she once had. She *“used to really hold a view that resilience was kind of individual and innate and this was a quality that you either had or*

*didn't*". Reflecting on attributions for her personal resilience during hard times facilitated the shift: *"I had support, I had family, I had society's idea of what intellect was ... resilience came from my experience and being born privileged."*

Discomfort with individualistic perspectives of resilience was discussed by three participants (none held an individualistic view themselves). It was felt that conceptual individualisation shifts responsibility away from wider socio-political influences, instead placing the onus on people and their systems to 'be resilient' despite exacting circumstances. Connie described:

*"the growth of [resilience] has happened at the same time as austerity's really kicked ... I think resilience can end up being quite individualised and static and is that ok to say ... "continue to be ok" ... when maybe what is happening in the system around the person isn't ok?"*

Rachel was the only participant who found it more difficult to identify people's resilience over time: *"I think I probably struggle a bit more now with seeing people's resilience ... over time it's got a bit harder."* Whilst Rachel could identify tangible reasoning for her growing challenge – *"cases that are more complex and there is less scope for big change"* – she used reflection and clinical supervision to work through this: *"I feel like that's something I think a lot about and try and notice when that is happening. If it is I talk about it in supervision."* These strategies were potentially effective for her as there were no other discernible differences in Rachel's conceptualisation or accounts of practice.

### **Clinical practice and engagement to bolster resilience**

Participants described working at four levels to foster resilience for their clients. They spoke about multi-layered interventions, often intervening at several levels concurrently.

**Direct working practices.** When working at the individual level, salient features of practice supporting people's resilience included: sharing belief in/hope for people, being strengths-focussed, collaboration/shared expertise and power, and building self-esteem and coping skills:

*"I just openly tell people that I think they're amazing ... I guess I'm there with him trying to instil a feeling of hope ... his resilience, which I know he has, just needs some nurturing."* (Rachel).

*"draw upon the things that they have managed ... and kind of emphasising that ... being a bit overexaggerated at times in order to bring attention to the exception"* (Maggie).

*"saying this therapy's half me and half you ... each of our skill sets ... acknowledging them as being experts of their own life."* (Abigail).

*"look at what you're capable of, look at what you bring, helping their self-esteem along and then practicing various skills for coping with horrible events and feelings."* (Natasha).

Participants also viewed various psychological therapies as directly relevant/conducive to resilience. These included narrative therapy, cognitive analytic therapy, dialectical behaviour therapy (DBT) and solution focussed therapy. For example, Stephanie stated *"He's engaged in DBT and this is helping him immensely with resilience ... with things like ... assertion and emotional regulation."*

**Working systemically.** All participants worked with direct caregivers to: 1) build resilience for the person via their system, and 2) build resilience within it. The first included training sessions and co-creating/sharing the person's history and psychological formulation with caregivers, to create sympathetic standpoints and valuable client-system relating. Sophie

explained, *“you try and increase the understanding, empathy and warmth toward the person which hopefully will help to foster better relationships.”* Second, bolstering resilience within the system itself was done by offering a *“safe”* listening space, normalising and validating difficult feelings about the work, recognising and illuminating systemic strengths and achievements, and co-creating action plans. Natasha’s strategies included:

*“systems have the answers it just might be a vehicle of trying to kind of help them have a different perspective ... we’re very much working together ... I think working to people’s strengths and promoting that ... helping people work together and seeing the strengths of each other”*

**Working with risk.** All participants described their risk assessment and management practices in relation to resilience. In line with requiring breadth of life experiences outlined earlier, everyone suggested the importance of positive risk-taking, as opposed to risk-averse practice. Sophie, for example, undertook: *“planned risk taking which is giving the chance to, in a scaffolded way, try things out, take risks”*. There was a consensus that stringent risk decisions led to over-protection, which hindered resilience. Being too risk-focussed held threats such as: *“she was infantilised and smothered, and her perceptions of her own dangerousness was just really elevated and inaccurate.”* (Hazel). All therefore endeavoured to balance either opportunities or human rights, with risk. Collaboration with clients was also inherent across half of participants’ accounts, where clients were involved in appraising their own risks. Abigail described collaboration and human-rights based approaches to working with risk: *“collaborative, it involves people in the process ... sits risks and rights together ... it might be that their rights are not being met and their risks are increasing because their rights are decreasing.”*

Further, to foster resilience participants described how they worked systemically to move systems away from risk aversion, and toward more flexible/positive approaches. Michelle explained that she: *“support[ed] staff teams to understand that the risks that they perceive aren’t necessarily always there or help them to see that a risk is changeable and how it is assessed and managed should be flexible.”*

**Wider socio-political engagement.** All participants agreed on the importance of macro influences on resilience, however only five outlined how they engaged broadly/socio-politically to bolster resilience for people with ID. Examples of this type of working included:

*“I’ve had some involvement in writing bits of policy”* (Connie).

*“I’m part of the learning disability special interest group and they have reps on various working parties ... and I suppose just by doing research ... it gets the broader themes out there.”* (Natasha).

*“setting up service user involvement groups ... enabling their rights and their voice to be heard about what changes they would want in systems.”* (Abigail).

Importantly, participants discussed discernible barriers to wider engagement. These included time and capacity, perceived knowledge and skill, and employer restrictions:

*“People have different levels of energy and time and physical resource and other commitments.”* (Jane).

*“that makes it really difficult ... knowing what to do, how to approach it ... where to go with things and who to tap into.”* (Natasha).

*“Some are brilliant at [social media] but they’ve not got an NHS contract ... if you’re in an NHS trust there’s a lot of messages about not speaking up ... that’s a significant barrier ... I’m not in a position to lose my job.”* (Connie).

Alison’s experience of NHS work-related restrictions around macro engagement had led her to pursue a new job within a social enterprise, with greater opportunities for this type of work (*“why not go and fight the cause?”*).

The experiences shared by participants, and the resultant theoretical model, are discussed below with reference to available literature, policy documents and potential implications.

### **Discussion**

This study addressed a research gap by exploring resilience amongst adults with ID, from the perspectives of Clinical Psychologists. The theoretical model explained how participants conceptualised and worked with resilience amongst this population. The study extends pre-existing ID research, concerned primarily with resilience amongst children (Gilmore et al., 2013), or family members (Grant et al., 2007).

Consistent with Windle’s (2011) conceptual definition, participants viewed resilience as comprised of adversity and adaptation to adversity, supported by a range of internal and external variables. The adversities discussed were consistent with prior ID research; magnified risk of abuse, isolation, stigma and poor health (Emerson & Baines, 2011; Walsh et al., 2003; Sobsey, 1994; Werner, Corrigan, Ditchman & Sokol, 2012; Landman, 2014). The present study supports earlier literature in that lifelong ID-related stigma (i.e. being negatively evaluated as ‘deficient’) is a significant social adversity facing this population (Green, Davis, Karshmer, Marsh & Straight, 2005).

Resilience research tends to focus on positive adaptation to major/significant life events. For example, in the context of cancer, sexual abuse and warfare (Dong et al., 2017; Hebert, Lavoie & Blais, 2014; Eakman, Schelly & Henry, 2016; Walsh et al., 2016). However, the current findings suggest that ongoing challenges in understanding amongst those with ID (which may outwardly be less apparent) can be unique, chronic adversities prompting resilience. Windle (2011) noted that chronic/persistent adversities can be considered ‘antecedents’ if they prompt resilience under “normal circumstances with a majority of people” (p. 158). Further research is indicated, then, to explore whether persistent understanding differences are commonly experienced as adversities relatable to resilience amongst people with ID.

Participants did not use the resilience language of ‘bouncing back’ to previous functioning as others have (Windle, 2011; Smith et al., 2008). Instead, they spoke of people with ID ‘coping with’ or ‘withstanding’ hardship, which did not necessarily mean ‘unscathed’. This suggests that people might experience adversity, be affected by it ‘negatively’, yet still experience resilience. Distress and resilience were not, for these participants, mutually exclusive for people with ID. This is again consistent with Windle (2011), who warned against viewing resilience as the absence of distress; indeed, distress as well as ‘getting through’ may be highly indicative of resilience.

Comparable to pre-existing conceptualisations (Windle, 2011), participants viewed resilience as a process and/or outcome (not an innate trait) which is ‘ever-changing’ depending on availability of resources, of which systemic and socio-political are crucial. The perceived dynamic nature of resilience is congruent with the notion that “resilience is not absolute, no one is simply resilient” (Rezaie, Nazari, Zaharakar & Smaelifar, 2013, p. 59). Windle’s (2011) domains of resilience resources resided “within the individual, their life and environment”,

p.12. The current findings further specify these domains amongst people with ID; intrapersonal, immediate systemic/interpersonal, and macro socio-political influences.

Participants identified individual-level assets related to resilience (emotional understanding/regulation skills, self-esteem, drive/persistence toward new experiences, autonomy in goal setting, bravery, hope and humour). Similar characteristics have been related to resilience outside of ID research (Tugade & Fredrickson, 2007; Veselska et al., 2009; Davey, Eaker & Walters, 2003; Youssef & Luthans, 2007; Cameron & Brownie, 2010). In the current study, these assets were symbiotic with features of immediate and socio-political systems.

This interplay of influences was important to participants, who took issue with the harm of individualistic perspectives of resilience. This view is shared by commentators on resilience in the lives of people with ID and beyond (Goodley, 2005; Northway, 2017; Harrison, 2013). These authors advise that focussing solely on individuals' internal sense of resilience shifts wider responsibility to make positive changes for people with ID. Participants herein felt it prejudicial to expect people with ID to 'be resilient' in unforgiving socio-political climates (e.g. the fiscal context, the open market of public health, and under-representation in society). This reflects the views of Northway (2017) and Harrison (2013) who reject the notion that people should be expected to cope within unjust circumstances, rather macro-transformation is necessitated. The harms of austerity and other broad contextual factors has been explored in generic mental health (Knapp, 2012; Wahlbeck & McDaid, 2012). A small amount of research exists within ID research, for example exploring the impact of individualism and de-collectivism (including day centre closures) (Power, Bartlett & Hall, 2016). However, investigating impacts of austerity and related policies must be addressed in ID research, to provide robust arguments for change facilitative of resilience.

The social model of disability does not view disability as residing within the person, rather people are disabled by inaccessible contexts (Rioux & Bach, 1994; Oliver & Barnes, 1998). Herein, participants' views were aligned with this model and, inversely, they subscribed to a social model of resilience whereby the process is enabled/hindered by context. A social model of resilience is perhaps salient for people with ID who, due to their differences, often rely on regular support from others (JCHR, 2008), "*which is probably quite different to somebody without [ID].*" (Hazel). The emergent social framework, and interplay of resilience influencers, aligns with the social ecology model of resilience (Ungar, 2011). This suggests that when considering resilience-enhancing/disabling variables, we should first explore context (social, cultural and physical ecologies), before turning to within-person variables. For Ungar (2011) and participants herein, responsibility and locus of control for resilience is shared across individuals and the contexts they inhabit.

Turning, then, to factors deemed important within social environments; breadth of life experience, ordinary relational lives, closeness with others, person-centred care, and systemic resilience. The first two are congruent with arguments proposed by Sellars (2011) in that people with ID require opportunities to experience risk and hardship, make mistakes, have ordinary opportunities and make choices, as adults without ID do every day. These opportunities (permitted/governed by care systems) were considered conducive to resilience; being denied them was 'overprotective' and diminished resilience. Needing emotional closeness with another (to converse with about hardship, trust and feel safe with) was considered important for experiencing resilience. This finding has a potential link with requiring the 'secure base' when feeling threatened (adversity) described in attachment theory, and has been related to resilience in this way in other fields (Ainsworth, 1989; Schuengel, Kef, Damen & Worm, 2010; Johnson et al., 2009). With respect to person-centred care, this assumes a central priority in the care of people with ID and is a focus in key strategy documents (Department of Health, 2009;

NHS England, 2015). Person-centred care accentuates the unique needs, preferences, choices and aspirations of the individual and their family in co-created care planning. Given these features of person-centred care, it seems unsurprising that participants linked this systemic practice with increased resilience for the individual. However, no prior literature could be identified which links person-centred care with resilience. Exploring both service user and care provider perspectives on whether person-centred care and resilience are linked may be a valuable and interesting area for future investigation.

Systemic resilience, discussed predominantly within staff teams, was directly related to individuals' sense of resilience. Systemic resilience was explicitly discussed as 'well-led, well-managed, well-supported' teams, where staff feel rewarded and able to raise concerns. More implicitly, participants also linked systemic resilience with working together, colleague-colleague appreciation of strengths, and feeling heard and emotionally validated. Grant et al. (2007) reviewed systemic resilience amongst families, where facilitative experiences included rewards, recognition, acknowledgment, and having structures for managing stressors. This therefore holds some similarities with the current findings. However, being a paid employee is qualitatively different to being a family member. For example, families face unique challenges in negotiating the relative versus carer role (Grant et al., 2007), whereas employees are accountable to an organisation and will negotiate within-team dynamics. This study offers a valuable starting point for future research, which could focus on how staff teams experience collective resilience and its relation to service user outcomes.

Grant et al. (2007) highlighted the roles of macro influences; the social, cultural and political 'holding environment' shaped and affirmed resilience at the individual level. These facets were also identified in the current study, though participants collectively felt that current macrosystems are unfavourable for fostering resilience amongst people with ID. All

participants described engagement with the individual, their immediate system, and risk management to promote resilience. However, only four described macro-level engagement through research, policy and supporting self-advocacy (Goodley, 2005). Comparable with other literature, participants readily discussed barriers to macro-engagement: time, capacity, self-perceived knowledge/skill, and perceived employer restrictions. Despite responsibilities to engage broadly, Clinical Psychologists can avoid entering the socio-political arena due to doubts about practical application, anxiety, and systemic pressures focussed more at the individual level (Attenborough, Hawkins, O'Driscoll & Proctor, 2000; Thompson, 2007).

Recent qualitative inquiry with 'activist-practitioner' Clinical Psychologists recommended: specific training to bridge the 'knowledge-policy' gap, macro-level work to be seen as a legitimate/valid use of Clinical Psychologists' time/competencies, and for Clinical Psychologists to be politically aware/active, from grassroots to government (Browne, 2017). In Alison's words, research is needed to understand how Clinical Psychologists can be supported to "*fight the cause*" of adversity, social injustice and reduced opportunities for people with ID, in favour of contexts more supportive of resilience (Windle, 2011). Such research might explore perspectives of senior stakeholders in healthcare, to identify whether barriers experienced by Clinical Psychologists are perceived or concrete. If barriers exist at this level it will be important to examine how organisations might support employees to affect change at broader levels. This research foci might have implications for Clinical Psychology training courses, Clinical Psychologists, their employing organisations, and ultimately the lives and resilience of people with ID.

Consistent with Sellars (2011) and the strategy document 'Valuing People Now' (Department of Health, 2009), participants felt that an emphasised risk focus and overprotection from risk/adversity is restrictive and impedes opportunity and resilience. Risk

aversion can reinforce deficit-focussed understandings of people with ID, can limit learning, and is at worst synonymous with abuse. Participants instead talked about flexibly balancing positive risk-taking/human rights/opportunity and risk when undertaking risk assessment and management. Such approaches have been aligned with choice facilitation, autonomy, inclusion and ‘ordinary’ lives for those with ID (Seale, Nind & Simmons, 2013; Greenhill & Whitehead, 2011); experiences which participants in the current study related to resilience. Underpinning participants’ clinical risk practices, and human rights-based approaches described elsewhere, is a commitment to participation, collaboration and a ‘life like any other’ (Greenhill & Whitehead, 2011; JCHR, 2008). The clinical implications related to this finding will be outlined later.

Resilience amongst people with ID invoked admiration amongst participants. The strengths and capabilities to withstand hardship incited powerful experiences such as Maggie’s, *“I’m always surprised and ... in awe of what people kind of go through ... There’s a lot that I learn from people that I work with”*. These viewpoints challenge stereotyped, deficit-saturated understandings of people with ID, where people are defined by limitations (Goodley, 2000; Windle, 2011). Instead, findings support a view of capability, strength and thriving, from which people without ID can learn. All clinicians shared their positive views of individuals, with the individuals themselves and care systems. However, these views should evidently be shared in macro-spheres to challenge views of passivism around people with ID in favour of views of activism and optimism (Goodley, 2005).

Participants described that resilience underpinned large parts of their clients’ lives and their clinical practices, however the construct was not always explicit. Construct latency may be explained by conceptual complexity and the notion that those considering and working with resilience may be confusing it with other constructs (Windle, Bennett & Noyes, 2011). Latency

may also be explained by resilience as a ‘metatheory’ which subsumes a multitude of psychological processes (Richardson, 2002), perhaps more readily accessible to Clinical Psychologists (e.g. emotional regulation or self-esteem). Further, Clinical Psychologists often use outcome measures to evaluate the impact of their clinical work. However, there is no gold standard for measuring resilience as it is difficult to measure and achieve internal validity (Windle et al., 2011). This study, and forthcoming research by Raye and Chadwick (2016), might go some way in resolving this issue for adults with ID, as indicators for understanding and measurement may be apparent.

### **Clinical Implications**

As invited by Emerson (2013), the study findings offer clinical implications congruent with fostering resilience amongst people with ID. It seems imperative that when assessing and fostering resilience amongst adults with ID, clinicians should consider the interplay of influences, from the level of the individual to macrosystemic factors. Multiple intrapersonal characteristics and variables were identified which, if bolstered, could foster resilience amongst people with ID. However, individualistic perspectives of resilience, which solely place responsibility on the person with ID to ‘be resilient’, should be challenged, and wider influences examined. Wherever possible, resilience and resilience-enabling support, within the caregiving system should be explored and strengthened. Clinical Psychologists in the current study gave many examples of how this can be supported by this particular profession. Their systemic practices were aligned with principles within national drivers of ID services, where the person *and* their caregiving system are at the centre, and support for carers is a key priority (NHS England, 2015).

However, immediate systemic experiences were interdependent with socio-political variables, such as governmental expenditure, legislation and societal attitudes. At this broader

level, it would be beneficial to challenge stigmatising societal assumptions and the overlooking/underrepresentation of people with ID. The current findings suggest that this, in part, could be tackled with greater (and more positive) representation of people with ID in media, social spaces, policy, and the distribution of public money. This broader-level work could be fronted by Clinical Psychologists. However, negotiations between Clinical Psychologists and their NHS superiors may first be beneficial, with the aim of clinicians feeling more supported and encouraged to engage socio-politically. Clinical Psychology training courses also have a responsibility to equip clinicians to practise within socio-political spheres, in the interests of affecting change at the individual level. Lastly, Clinical Psychology courses, and indeed training of any professional who may work with people with ID, could embed positive, collaborative, and human-rights based approaches into risk assessment and management training. Participants in the current study linked these approaches with resilience-enhancing opportunities for the person.

### **Limitations and Strengths**

Several study limitations are important to note. First, grounded theory seeks diversity and a range of experience within participant samples. In the current study, lack of diversity is a potential limitation. For example, the sample was entirely female, and the voices of male Clinical Psychologists are missing. Clinical Psychology is a predominantly female profession and no males responded to study advertisements. Additional steps to recruit males would have been undertaken if theoretical sampling indicated this. However, no gender issues emerged which warranted specific recruitment of men, therefore the impact of this limitation might be reduced. Second, participants worked in services for people with ID who had additional health and support needs. Participants therefore likely had a skewed perspective of both adversity and adaptation to adversity. This study is perhaps not representative of those with ID who do not

need to access NHS services, nor Clinical Psychologists beyond this sample in one English region. For instance, there is a human rights-based clinical priority in the local study context, which may have underpinned the model in some way. However, as this was a grounded theory study, generalising the findings was not an intention. Third, the first author was a Clinical Psychologist in training with an interest in working with people with ID. This may have offered an advantage through shared experience with participants, however may have also led to a priori assumptions about the profession and resilience amongst people with ID. Memos, supervision and independent coding of transcripts across authors helped to reduce this potential. Nevertheless, the researcher's position as a trainee in the same profession may have biased the participants' responses, for example by participants presenting an idealised professional self. Finally, while service user involvement featured in the early direction of the study and developing an easy-read research summary, this study may have been strengthened if there was greater involvement of experts by experience throughout study design and development.

The strengths of the study will now be discussed. To a currently scant area of research, this study adds novel understandings about resilience amongst adults with ID, and influences and practices which support this process. The findings portray those with ID as capable, resilient people whom 'typically developing' people can learn from. This offers a welcome contribution to the deficit-focussed paradigm of ID, which might progress much-needed positive representations (JCHR, 2008). Sellars (2011) invited more balanced and positive approaches to risk assessment and management. The current findings illuminate how professionals do so with collaboration and human rights-based approaches. As noted earlier, this has important research and practice implications. Further, whilst commentators have warned against the individualistic focus of resilience in ID in research and practice (Northway, 2017), current findings promote a social model of resilience in which the influence of

caregiving systems and society, culture and politics are paramount. The study highlights important foci for future research and practice, for example supporting Clinical Psychologists to affect change at broader levels in the interests of improving the lives of people with ID. Finally, the methodological approach and flexibility allowed rich and detailed accounts to be obtained which supported model development. Methodological processes were robust through closely following guidelines by Charmaz (2014), by engaging the research team in the coding strategy and interpretation, and by recruiting a Clinical Psychologist for a validity check of the developing theory contextualised in her experiences.

## **Conclusions**

Resilience amongst adults with ID was conceptualised by Clinical Psychologists as a dynamic process or outcome, shaped by intrapersonal, systemic/interpersonal, and socio-political influences. Aside from ‘bouncing back’ not being talked about by these participants, the conceptual definition by Windle (2011) broadly accounts for the understanding of resilience amongst people with ID from the perspective of Clinical Psychologists. There was a rejection of individualistic notions of resilience, with a greater emphasis on the importance of contextual and environmental factors, in line with Ungar (2011). Participants experienced many ways in which immediate systems bolstered opportunities for individuals’ resilience. However, it was felt strongly that socio-political issues facing people with ID are detrimental for resilience. Despite the importance placed on this domain of influence, Clinical Psychologists experienced barriers to engaging at this level to foster resilience; a finding with important research and clinical implications.

The current study adds knowledge of the range of assets, resources and practices which support and hinder resilience amongst people with ID, indicating practice and research

implications. It will be important to compare lived experiences of resilience from the perspectives of adults with ID, with these findings, to facilitate a comprehensive understanding of resilience for this population. Indeed, professional and academic stakeholders alone should not determine what constitutes positive adaptation for those facing their own distinct adversities (Ungar, 2011). Finally, the findings highlight the resilience, strengths and capabilities of people with ID, and go some way in further challenging the paradigm of deficit.

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## Appendix 1

### Author Guidelines for the Journal of Applied Research in Intellectual Disabilities

**General.** The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

**Manuscript types accepted.** *Original Articles, Review Articles, Brief Reports, Book Reviews* and *Letters to the Editor* are accepted. *Theoretical Papers* are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

#### Manuscript Format and Structure.

**Format.** Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at [http://authorservices.wiley.com/bauthor/english\\_language.asp](http://authorservices.wiley.com/bauthor/english_language.asp). All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

**Structure.** All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

**Cover Page:** A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

**Running Title:** A short title of not more than fifty characters, including spaces, should be provided.

**Keywords:** Up to six key words to aid indexing should also be provided.

*Main Text:* All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables should be submitted as a separate file.

*Style:* Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:

- Include all figure legends, and tables with their legends if available.
- Do not use the carriage return (enter) at the end of lines within a paragraph.
- Turn the hyphenation option off.
- In the cover email, specify any special characters used to represent non-keyboard characters.
- Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
- Use a tab, not spaces, to separate data points in tables.
- If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

#### **References.** APA - American Psychological Association

References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

**Tables, Figures and Figure Legends.** Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption. Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

## Appendix 2

### Methodological quality appraisal tool guidelines (QualSyst)

Kmet et al. (2004) outline fourteen quality criteria for appraising quantitative studies as follows:

Criteria	YES (2)	PARTIAL (1)	NO (0)	N/A
1	Question / objective sufficiently described?			
2	Study design evident and appropriate?			
3	Method of subject/comparison group selection or source of information/input variables described and appropriate?			
4	Subject (and comparison group, if applicable) characteristics sufficiently described?			
5	If interventional and random allocation was possible, was it described?			
6	If interventional and blinding of investigators was possible, was it reported?			
7	If interventional and blinding of subjects was possible, was it reported?			
8	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?			
9	Sample size appropriate?			
10	Analytic methods described/justified and appropriate?			
11	Some estimate of variance is reported for the main results?			
12	Controlled for confounding?			
13	Results reported in sufficient detail?			
14	Conclusions supported by the results?			

An example of how to arrive at the ‘yes’, ‘no’, ‘partial’ or ‘N/A’ rating is provided here for criteria one (Kmet et al., 2004):

“1. Question or objective sufficiently described?

**Yes:** Is easily identified in the introductory section (or first paragraph of methods section). Specifies (where applicable, depending on study design) *all* of the following: purpose, subjects/target population, and the *specific* intervention(s)/association(s)/descriptive parameter(s) under investigation. A study purpose that only becomes apparent after studying other parts of the paper is *not* considered sufficiently described.

**Partial:** Vaguely/incompletely reported (e.g. “describe the effect of” or “examine the role of” or “assess opinion on many issues” or “explore the general attitudes”...); *or* some information has to be gathered from parts of the paper other than the introduction/background/objective section.

**No:** Question or objective is not reported, or is incomprehensible.

**N/A:** Should not be checked for this question.”

The process for obtaining overall quality scores was as follows (Kmet et al., 2004):

“For the quantitative studies, 14 items [see above] were scored depending on the degree to which the specific criteria were met (“yes” = 2, “partial” = 1, “no” = 0). Items not applicable to a particular study design were marked “n/a” and were excluded from the calculation of the summary score. A summary score was calculated for each paper by summing the total score obtained across relevant items and dividing by the total possible score (i.e.:  $28 - (\text{number of “n/a”} \times 2)$ ).

Total sum = (number of “yes” \* 2) + (number of “partials” \* 1)

Total possible sum =  $28 - (\text{number of “N/A”} * 2)$

Summary score: total sum / total possible sum”

### Appendix 3

#### Request for Clarification from the Authors of an Excluded Study

##### 2013 Article Inquiry



Williamson, Hannah

Tue 03/04, 11:41



Dear Joanne Brooker and colleagues,

I am currently conducting a systematic review on the effectiveness of staff interventions for people working in Intellectual Disability Services.

My searching yielded your very interesting paper, "Evaluation of an Occupational Mindfulness Program for Staff Employed in the Disability Sector in Australia, 2013" among the results.

In order to either include or exclude your study from my review, I hoped you could provide me with further details.

Throughout the paper you mention disability support staff and the disability sector, however could you kindly specify which type of disabilities staff in your study worked with. Were learning disability/intellectual disability staff among your sample or not? If they were, did they work with children or adults with learning/intellectual disabilities?

Any additional information on this would be greatly appreciated and I would of course keep you updated on progress with my review in the near future if you happen to be interested.

I very much look forward to hearing from you

Kind regards  
Hannah

**Hannah Williamson**  
Trainee Clinical Psychologist  
University of Liverpool  
Whelan Building  
Brownlow Hill  
Liverpool  
United Kingdom  
L69 3GB

## Appendix 4

### Ethical Approval: University of Liverpool



Health and Life Sciences Committee on Research Ethics (Psychology, Health and Society)

20 February 2017

Dear Dr Bennett,

I am pleased to inform you that your application for research ethics approval has been approved. Details and conditions of the approval can be found below:

Reference:	1549
Project Title:	How do Clinical Psychologists think about resilience among people with Intellectual Disabilities?
Principal Investigator/Supervisor:	Dr Kate Bennett
Co-Investigator(s):	Miss Hannah Williamson, Dr Andrea Flood
Lead Student Investigator:	-
Department:	Psychological Sciences
Reviewers:	Prof Fernand Gobet, Miss Rosie Mansfield
Approval Date:	20/02/2017
Approval Expiry Date:	Five years from the approval date listed above

The application was **APPROVED** subject to the following conditions:

#### Conditions

- All serious adverse events must be reported via the Research Integrity and Ethics Team ([ethics@liverpool.ac.uk](mailto:ethics@liverpool.ac.uk)) within 24 hours of their occurrence.
- If you wish to extend the duration of the study beyond the research ethics approval expiry date listed above, a new application should be submitted.
- If you wish to make an amendment to the research, please create and submit an amendment form using the research ethics system.
- If the named Principal Investigator or Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore it will be necessary to create and submit an amendment form using the research ethics system.
- It is the responsibility of the Principal Investigator/Supervisor to inform all the investigators of the terms of the approval.

Kind regards,

Health and Life Sciences Committee on Research Ethics (Psychology, Health and Society)

[iphsec@liverpool.ac.uk](mailto:iphsec@liverpool.ac.uk)

0151 795 5420

## Appendix 5

### Permission to Conduct Research: Health Research Authority



Health Research Authority

Dr Kate Bennett  
Eleanor Rathbone Building  
School of Psychology  
University of Liverpool  
L69 7ZA

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

17 May 2017

Dear Dr Bennett

#### Letter of HRA Approval

<b>Study title:</b>	<b>How do Perceptions of Resilience in People with Intellectual Disabilities Influence Clinical Practice? A Grounded Theory of the Perspectives of Clinical Psychologists</b>
<b>IRAS project ID:</b>	<b>223456</b>
<b>Protocol number:</b>	<b>UoL001293</b>
<b>Sponsor</b>	<b>University of Liverpool</b>

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

#### Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

IRAS project ID	223456
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It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

### Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

### After HRA Approval

The attached document “*After HRA Approval – guidance for sponsors and investigators*” gives detailed guidance on reporting expectations for studies with HRA Approval, including:

- Working with organisations hosting the research
- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

### HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **223456**. Please quote this on all correspondence.

IRAS project ID	223456
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Yours sincerely

Kevin Ahmed  
Assessor

Telephone: 0207 104 8171  
Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: *Mr Alex Astor, Sponsor Contact, University of Liverpool*  
*Mr Phil Elliot, R&D contact, Cheshire and Wirral Partnership NHS Foundation Trust*  
*Miss Hannah Williamson, Student, University of Liverpool*

IRAS project ID	223456
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### Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Study Advertisement]	1	09 February 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Approval]	1	01 February 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance 2017-2016]		
Interview schedules or topic guides for participants [Interview Schedule]	1	09 February 2017
IRAS Application Form [IRAS_Form_29032017]		29 March 2017
Letter from sponsor [Sponsor Letter]	1	01 February 2017
Non-validated questionnaire [Questionnaire (non-validated)]	1	09 February 2017
Other [Statement of Activities]	1	04 May 2017
Other [Schedule of Events]	1	04 May 2017
Participant consent form [Consent form]	1	09 February 2017
Participant information sheet (PIS) [PIS]	1	09 February 2017
Referee's report or other scientific critique report [Research Review Committee Approval ]		05 December 2016
Research protocol or project proposal [Research Proposal]	4	26 February 2017
Summary CV for Chief Investigator (CI) [CI CV]	1	13 September 2016
Summary CV for student [Student CV]	1	03 March 2017
Summary CV for supervisor (student research) [CI/Supervisor CV]	1	13 September 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Lay Summary]	3	10 November 2016

IRAS project ID	223456
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## Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

**For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.***

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Mr Alex Astor  
 Tel: 0151 794 8739  
 Email: sponsor@liv.ac.uk

### HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor has submitted the HRA Statement of Activities and intends for this to form the agreement between the sponsor and the participating NHS organisations.  The sponsor is not requesting, and does not require any additional contracts with study sites.

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Section	HRA Assessment Criteria	Compliant with Standards	Comments
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study.
4.3	Financial arrangements assessed	Yes	No application for external funding has been made. No study funding will be provided to sites, as detailed at Schedule 1 of the Statement of Activities.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Not Applicable	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

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### Participating NHS Organisations in England

*This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.*

All participating NHS organisations will undertake the same study activities. There is therefore only one study site 'type' involved in the research.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at [hra.approval@nhs.net](mailto:hra.approval@nhs.net). The HRA will work with these organisations to achieve a consistent approach to information provision.

### Confirmation of Capacity and Capability

*This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.*

NHS organisations in England that are participating in the study **will be expected to formally confirm their capacity and capability** to host this research.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

### Principal Investigator Suitability

*This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).*

A Local Collaborator would be required at each site to facilitate recruitment of participants through internal mailout, to arrange access on site for the student researcher, and book rooms for the interviews.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

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### HR Good Practice Resource Pack Expectations

*This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken*

A Letter of Access will be required for the student researcher to come on the host NHS site premises to undertake research activities, should other prior contractual arrangements not be in place. DBS checks and occupational health clearance are not required as no clinical area should be accessed and no contact with patients should occur for the purpose of the research.

### Other Information to Aid Study Set-up

*This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.*

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

**Appendix 6**  
**Study Advertisement**

**RESEARCH PARTICIPANTS NEEDED**

**HOW DO PERCEPTIONS OF RESILIENCE IN PEOPLE WITH A  
LEARNING DISABILITY INFLUENCE CLINICAL PRACTICE?**

- Are you an NHS Clinical Psychologist working with adults with a learning disability?
- Have you worked with this client group for at least 12 months?
- Are you employed by either: xxxxxxxx NHS trusts?

If you have answered yes to the above questions you are invited to take part this research project.

The research will be looking at how Clinical Psychologists think about resilience in people with a Learning Disability (LD), and how this might influence clinical practices.

By advancing knowledge about resilience in LD it might be possible to think about interventions and practices which promote resilience in this client group.

Participating will involve a one hour face-to-face interview about your views and experiences as a professional working with this client group.

Once the research is complete you can choose to be informed of the findings.

This research is part of a Clinical Psychology doctoral thesis.

**If you wish to learn more about taking part please contact:**

**Hannah Williamson (Lead Researcher) on**

**[hannah.williamson@liverpool.ac.uk](mailto:hannah.williamson@liverpool.ac.uk) Supervised by Dr. Kate Bennett**  
**[k.m.bennett@liverpool.ac.uk](mailto:k.m.bennett@liverpool.ac.uk)**

**Appendix 7**  
**Participant Questionnaire**

**Please indicate your responses to the questions below, or provide your responses in the space provided.**

1. I am an NHS Clinical Psychologist currently working in a service for adults (>18 years) with intellectual disabilities

**Yes**                      **No**

2. I have been in an NHS post with adults with intellectual disabilities for a minimum of twelve months

**Yes**                      **No**

3. I am English Speaking

**Yes**                      **No**

4. Age: ..... years

5. Gender: .....

6. What is your NHS banding: .....

7. The type of service I work in is:

a. Inpatient unit    b. Community    c. Other (please specify)

.....  
.....

8. Is your service currently:

a. Well-resourced                      b. Under-resourced                      c. Mixed (please give detail e.g. well- resourced with some disciplines and under-resourced with others)

.....  
.....

9. Is your service:

a. Newly developed

b. Long-standing and established

10. Please give detail of the eligibility criteria enabling people to access your service:

.....  
.....

11. Please summarise a typical distribution of your clinical responsibilities per week in percentages

- Direct clinical work.....%
- Systemic work.....%
- Consultancy.....%
- Teaching/training.....%
- Supervision.....%
- Service development.....%
- Research/Audit.....%
- Other (please state).....%
- Other.....%
- Other.....%

12. Please briefly describe the theoretical orientation/the approaches you draw on most frequently in your clinical work:

.....  
.....  
.....  
.....

13. Regarding service user support needs, do you predominantly work with:

- a. People with profound intellectual disabilities and high level of support needs
- b. People with moderate intellectual disabilities and moderate support needs
- c. People with mild intellectual disabilities and low levels of support needs
- d. A range of support needs (please give an estimate of the distribution e.g. 10% A; 45% B; 45% C)

.....  
.....  
.....

14. Time since qualifying as a Clinical Psychologist: ..... years  
..... months

15. Time spent working as a Clinical Psychologist with people with Intellectual Disabilities: ..... years ..... months

16. My Clinical Psychology Doctorate was completed at:  
..... university

## Appendix 8

### Participant Information Sheet

Thank you for showing interest in taking part in this research project. It is important that you understand the following information before you decide if you wish to participate or not.

#### **What is the research about?**

The research will explore Clinical Psychologists' understandings of resilience in people with Intellectual Disabilities (ID), and in what ways their understandings influence clinical practice.

#### **What is the purpose of the research?**

The research is being carried out as resilience research in the ID population is currently limited. By understanding more about resilience in this client group and how this can influence clinical practice, we may be able to promote interventions and practices that bolster resilience for people with ID in the future.

#### **Which organisations have approved this research?**

The University of Liverpool has provided Sponsorship and Ethical Approval for this research. The Health Research Authority (HRA) has given approval for the research to take place with NHS staff. Several NHS trusts in the North-West have given confirmation of capacity and capability for the research to take place.

#### **What will participation in this research involve?**

If you decide to participate, a time and place to meet with the lead researcher will be arranged. This will be a place within your NHS trust. When we meet, you can ask any questions you may have about the research. I will ask you to sign a consent form to ensure that you understand what participation will involve. We will carry out a face-to-face interview (approximately one hour) which will broadly cover your conceptualisation of resilience in people with ID, and ways in which this influences your clinical work. The interview will be audio recorded so it can be typed and analysed later.

#### **What will happen to the results?**

Interviews will be collated, analysed and written up into a doctoral thesis and empirical paper. Both will be submitted to the University of Liverpool in partial fulfilment of the degree of Doctor in Clinical Psychology. The empirical paper will be submitted for publication to an intellectual disability journal. If you wish, you can choose to be informed about the research findings.

#### **How will confidential information be protected?**

Any identifiable information about you or others (e.g. staff or service users) will be removed from write ups of the interviews to protect confidentiality. You will be given a unique identification number in order that the lead researcher knows which interview corresponds with which participant. Only the lead researcher will know your name. All information you provide will be for the purposes of the research only. However if during interviewing the lead researcher becomes aware of any potential harm to others, information may need to be shared with appropriate services in the interests of safeguarding.

#### **Do I have to participate and when do I need to decide by?**

Participation is entirely voluntary. Please contact the lead researcher (see below) within one week of receiving this information sheet to inform if you wish to participate or not. If you have not contacted the researcher within one week the lead researcher will contact you. If you do not wish to participate you do not have to provide a reason. If you wish to participate initially, and then later change your mind, you can withdraw from the research at any point up until the end of March 2018. You will not have to provide a reason for this.

**Please contact Hannah Williamson ([Hannah.williamson@liverpool.ac.uk](mailto:Hannah.williamson@liverpool.ac.uk)), Supervised by Dr Kate Bennett ([kmb@liverpool.ac.uk](mailto:kmb@liverpool.ac.uk))**

## Appendix 9

### Participant Consent Form

**Research Project:** How do Perceptions of Resilience in People with Intellectual Disabilities Influence Clinical Practice?

Thank you for agreeing to take part in this research.

Please place a tick beside each statement below and sign the bottom of the page to show that:

1. You have read and understand the information sheet provided.
2. You have been given time to consider participation.
3. You have been given the opportunity ask additional questions about the research.
4. You are aware that all identifiable information about you and others will be protected, and confidentiality will only be broken if a safeguarding issue is identified.
5. You give your informed consent to participate in this research.
6. You understand that participating is voluntary and you can change your decision until the end of March 2018 without having to provide a reason.

Participant Name	Signed	Date

Lead Researcher	Signed	Date

Please tick this box if you would like to receive a summary of the research findings when available.

Thank you.

## Appendix 10

### Interview Schedule

1. Can you tell me in your own words what you understand the term 'resilience' to mean?
  - Prompt: How do you define the term/construct?
  - Prompt: Is it a trait, process or outcome/fixed or acquired, dynamic construct
  
2. In your view, how relevant is the construct of resilience to people with ID?
  - Prompts: Are people with ID able to demonstrate resilience?
  - Any similarities/differences with resilience in the general population?
  
3. How do you know/recognise when someone with ID is demonstrating resilience? Can you demonstrate your answer with case example(s)?
  - Prompts: What does resilience in people with ID look like?
  - What might you or others notice?
  - How do the lives of people with ID demonstrating resilience differ from those who do not demonstrate resilience?
  
4. What do you perceive to be the factors that facilitate resilience in people with ID?
  - Prompts: Internal/external/ other
  - Prompts: Illustrate answer with case example(s)
  
5. What do you perceive to be the factors that hinder resilience in people with ID?
  - Prompts: Internal/external/ other
  - Prompts: Illustrate answer with case example(s)
  
6. In your view, do the factors you have discussed interact in any way?
  - Prompts: How are they related to/associated with one another?
  - Do any factors predict the presence of others?
  - Are any factors prerequisites for others to be present/important?
  - Does the presence of any factor counteract others?
  
7. How do you perceive your personal view of resilience in people with ID to influence the way you work with this service user group?
  - Prompts: Do your ideas and experiences of resilience in this group have implications for your practice?
  - Does your view influence your practice positively/negatively?
  - Does your view influence direct work/systemic work/consultancy and MDT working/teaching etc.?
  - Does your view influence the models/approaches you draw on?
  - Does your view influence your risk assessment and management?
  - Have you noticed changes in your view of resilience over time, and subsequent changes in the way you work?

8. Do you have any other views/comments about resilience in people with ID?

Prompt: Any other views/comments about how perceptions of resilience in people with ID can influence practice?

## Appendix 11

### Reflexive Statement (Prior to Undertaking Interview One)

I became interested in working with people with ID as a support worker working into forensic ID services in Middlesbrough in 2012. I found myself enjoying working with this population, enjoying the challenge of adapting my communicative style based on the individual I was speaking with. I found myself irritated at times by the stringent restrictive practices placed around people with ID in this setting, and began reflections on the implications this must have for these clients' opportunities for growth, development and goal attainment. It was here I noticed a passion reflecting on fairness, equality and justice when working with this population, who for the majority of their lives had been marginalised, and it seemed more so now than ever before. I felt frustrated as in my role as a support worker, with no fixed base and no supervision, I did not feel empowered enough to speak up about my concerns. I wondered whether my feeling disempowered mirrored the disempowerment of those I was working with.

I then secured a position as an assistant psychologist working into ID services in Cumbria. One of my main tasks here was the eligibility assessment to assess for ID, focussed on measures of cognitive and adaptive abilities. Although I enjoyed this experience thoroughly, learnt a great deal and helped people to understand themselves and their lives in a different way, I found myself downtrodden by the continued focus, based on the assessment focus, on the things people found difficult and their 'impairments'. It was through other work in this post, that I was able to speak with people with ID who, despite some harrowing and traumatic experiences (repeatedly throughout their life) were living meaningful lives, had talents and daily occupation, had networks of friends and families, were able to access the community and generally seemed to be enjoying life.

I was struck by one particular young adult male I will name Josh (pseudonym). Josh had contracted an illness at age 13 causing inflammation on the brain which led to his support needs being considered best met by learning disability services. Prior to the age of 13 Josh reflected that he was a "rough un", "hanging about with the wrong crowds about town" and "would take the piss out of people like this (referring to those he shared his day centre with)". He reflected that a change in his cognitive and adaptive abilities at 13 had "made him a better person"; that he was nicer to his family, that he saw himself as a mentor for other people supported by learning disability services, that he was a good friend and did not get into trouble. This got me reflecting upon how someone, given such a significant, intuitively negative, life event was able to adapt to it and frame it in such a positive way. This sparked my interest into reading and reflecting on positive psychological variables such as resilience in this population. I am someone who has experienced people with ID as extremely resilient at times and must be aware of my own belief when interviewing – it is not a guarantee that participants will see this population as able to experience resilience – I must take care not to impose this viewpoint.

I stored the above case experience away for several years until I picked it up again when commencing this research project. During those years I pursued a MSc in health psychology at Teesside University, where the research focus was heavily qualitatively focussed, divergent to my undergrad training which had very little focus on qualitative research methods. I found qualitative research methods fascinating and challenging. I noticed that such approaches fit well with my belief system; that there is no objective truth, rather that there are endless, multiple truths subjectively experienced by individuals and groups, that 'truths' are dynamic and can be socially and co-constructed amongst people and systems. This personal learning point stayed with me throughout

my Clinical Psychology training, were I felt a congruence between qualitative research methods and Clinical Psychology practice (assessment and formulation in particular - where individuals/systems and I would co-construct meaning about a particular issue facing a person or team, in order to think about what might help). I noticed that the 'what might help' part is framed as *interventions* within practice, and *clinical implications* within qualitative research.

In going into this first interview I hold these above experiences in mind. I am experiencing some anxiety about my skills as a qualitative interviewer and analyser, driven by a strong desire to 'get it right' and produce research which might change the way people with ID are held in mind and supported to develop resilience and thrive.

## Appendix 12

### Example of a Memo: Maggie

I remember walking out of this interview and feeling that it had gone well – with a breadth and depth of information covered - and also that I had agreed with most of what the participant was saying strongly, therefore was very aware and mindful of the urge to respond in a non-neutral or potentially leading way. On listening back over the tape on the drive home I felt that I had managed this well. However, on reading back over the transcript I am noticing some *potentially* leading questions which may have meant that my agreement was leading me to make some assumptions. I must make a greater effort in future interviews to avoid this and discuss in supervision.

Very drawn to the conversation around mistakes being made and that we all (with a learning disability or not) need to fail and work out what we do not want, to then be able to move toward what we do. Participant talks about the anxiety in systems, which is underpinned by care and protection, driving them to prevent peoples' mistakes and failures, which then prevents resilience development and then adversities in future are then harder to manage/adapt to. The clinician very much open to trying out different ways of supporting the individual to make mistakes in a safe way which seems like a counter approach to direct some staff she encounters.

All participants, including this one, are talking about the wider socio-political context and the impact that this has on all levels of the system, down to the individual. For this first time this participant speaks to the current commissioning and tendering arrangement around services and the impact this has upon staff teams and families, which inevitably impacts the individual.

Noticing that I am becoming quicker at coding interviews at this stage – wondering if this is evidence of validity of the coding structure; that it is making sense within new interviews. However, always some new initial codes coming through which is thought-provoking and has me reconsidering and flitting back to earlier interviews. Wondering however whether speed is reflective of time pressures the closer I move to the deadline – Plan: quality checking myself by revisiting transcripts and codes the following day/s.

Again, as with other interviews, something I was not expecting was the combined approach at many different levels clinicians take – for example sharing a collaborative formulation with the staff team, or considering change targets all together with the person and their team, including negotiations. Wondering whether this is a practice specific to LD given the history of limited control and autonomy over their lives and therefore clinicians are very attuned to practices which counter this.

Very much moved by the closing comment of the clinician - that she is not only in awe of people with a learning disability who survive, but also that she personally learns a lot from the people she supports. I feel this type of narrative would be so powerful for many to hear – particularly people who are perhaps new to working with people with ID.

### Appendix 13

#### Initial and Focussed Codes Subsumed within Core Conceptual Categories

Core conceptual category	Focussed codes	Initial code examples
Making sense of resilience	<p>Adversities experienced</p> <p>Intrapersonal influences</p> <p>Immediate systemic/interpersonal influences</p> <p>Macro socio-political influences</p>	<p>Living with ID as adversity</p> <p>Day-to-day understanding difficulties</p> <p>Having multiple adversities</p> <p>Increased exposure to adversities</p> <p>Experiencing abuse</p> <p>Being misunderstood, marginalised, excluded</p> <p>Being stigmatised</p> <p>Having self-esteem</p> <p>Having hope</p> <p>Being driven toward new experiences</p> <p>Engaging in humour</p> <p>Bravery</p> <p>Being autonomous in goal setting</p> <p>Having emotional literacy skills</p> <p>Having emotional regulation skills</p> <p>Breadth of life experience encouraged</p> <p>Being allowed to make mistakes</p> <p>Needing closeness with others</p> <p>Having person-centred care</p> <p>Having ordinary relational lives</p> <p>Systemic resilience</p> <p>Role of governmental expenditure and cuts</p> <p>ID representation in policy/legislation</p> <p>Cultural attitudes and behaviour</p> <p>ID representation in society and media</p>



	<p>Wider socio-political engagement</p> <p>Barriers to wider work</p>	<p>Being collaborative with client  Supporting systems in flexible risk practices  Supporting systems in positive risk practices</p> <p>Writing policy  Engaging with special interest groups  Being on working parties  Contributing to research  Setting up service user involvement groups  Leaving NHS job to “fight the cause”</p> <p>Having time and capacity pressures  Questioning personal knowledge/skill level  Perceived employer restrictions  Questioning political position of professional body</p>
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Initial codes	Transcript excerpt	Focussed codes	Conceptual category
<p>Being stigmatised</p> <p>Increased exposure to adversity</p> <p>Experiencing abuse</p> <p>Greater relevance of construct, as greater adversity</p> <p>Resilience as coping and getting through</p> <p>Expressing awe and reverence</p>	<p><b>Michelle:</b> I think its extremely relevant. It’s a social construct isn’t it, learning disability, but it’s a label that is surrounded by negative views I guess. Even when people are born and I guess a lot of the literature talks about shame or guilt and it’s not the (air quotes) perfect child. To be born into a world where a label you’re given is perceived so negatively by society and then how do you go through life with that. There’s then all the other literature about being with learning disability being more vulnerable, more at risk of being abused, and all of those other things. So I guess there’s an idea that if you have a learning disability you may well experience more adversity in your life and therefore you are going to have to somehow navigate your way through that and it feels like resilience has got to be an important part of that.</p> <p>...</p> <p>If I were to think about people with a learning disability would statistically be seen as people who come across more adversity in their lives than the general population and therefore would be more likely to display resilience than the general population. I suppose that’s maybe a distinguishing feature in my view, so the idea that you almost have to have more resilience when living with a learning disability because of the greater adversity you are likely to face. How do you cope with that, how do you find your way through that? But somehow people do and I’m surprised everyday by people’s strength to overcome things.</p> <p>....</p>	<p>Adversities experienced</p> <p>Adversities experienced</p> <p>Adversities experienced</p> <p>Construct qualities and relevance</p> <p>Construct qualities and relevance</p> <p>Clinician experience</p>	<p>Making sense of resilience</p> <p>Clinician experience</p>

<p>Needing closeness with others</p>	<p>There's definitely something about the support from others and most of the people that I work with do have some level of support, whether it be family or carers. There's something about those support people, how they are, that promotes some of that resilience. You know, its just that basic stuff</p>	<p>Interpersonal and systemic influences</p>	<p>Making sense of resilience</p>
<p>Having person-centred care</p>	<p>of being able to listen to the person, just kind of acknowledging what they want, kind of having the ability to think through whether a person is finding something difficult and why that might be. I guess I suppose if support networks or someone in it has gone the extra mile for someone it's just letting that person know that they are important and they are cared for and that's so important.</p>	<p>Intrapersonal influences</p>	<p>Making sense of resilience</p>
<p>Having self-esteem</p>	<p>Interviewer: Yes, anything else?</p>	<p>Macro socio-political influences</p>	<p>Making sense of resilience</p>
<p>Role of governmental expenditure</p>	<p>Michelle: Well I guess I'm thinking about the wider context too, you know there's lots of people who could do with a lot more support but because of funding issues and all of that, they're unfortunately not in that situation. I'm thinking generally about all of my cases and when there's been support that's really proactive and that people have taken the time to learn about the person, consider their needs and get an understanding about that person, even if it's just as basic as the best way to communicate with them, that's just so helpful for the person in making</p>	<p>Interpersonal and systemic influences</p>	<p>Making sense of resilience</p>
<p>Having person-centred care</p>	<p>life a little easier but also that they matter. Both of those things are important</p>	<p>Macro socio-political influences</p>	<p>Making sense of resilience</p>
<p>Role of governmental expenditure</p>	<p>for resilience development I think. It feels like there's a wider systemic issue too, about the structures around people. This isn't always set up for promoting resilience or supporting people's resilience. I guess I touched upon that in terms of social care and funding and people having enough support, you know, often people are just placed in inappropriate environments which is only going to inhibit resilience really.</p>	<p>Interpersonal and systemic influences</p>	<p>Making sense of resilience</p>

