

# Experiences of mental health professionals providing services to adults with intellectual disabilities and mental health problems

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# Experiences of mental health professionals providing services to adults with intellectual disabilities and mental health problems: A systematic review and meta-synthesis of qualitative research studies

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## Abstract

**Background:** Mental health professionals play an important role in providing care and treatment for adults with intellectual disabilities. A number of studies use qualitative methods to explore the experiences of these professionals and their perspectives regarding the mental health services for this population. A systematic review using meta-ethnographic approach was undertaken to summarise this research. **Method:** A systematic search found 14 relevant studies which were critically appraised. Key themes from these studies were extracted and synthesised. **Results:** Three main themes were identified: 1) Understanding the person, 2) Relational interaction and 3) Organisational factors. **Conclusions:** The findings of this review identified the issues mental health professionals raised in relation to their work. They described the complex presenting problems as intense yet fulfilling therapeutic relationships with their clients and their wish to improve their knowledge and skills. They identified organisational issues that need to be addressed to improve staff morale and efficiency.

## Keywords

intellectual disabilities, mental health professionals, qualitative research, services, staff experiences

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## Introduction

Many governments have guidelines and legislation to promote access for people with intellectual disabilities to mainstream services. For example, the UK government published a document entitled *Valuing People* (Department of Health, 2001) to encourage accessibility of mainstream services for people with intellectual disabilities. Trollor (2014) recommends accessible mainstream as well as specialist mental health services for this population in the UK. A recent review indicates that barriers to mental health services are related to deficits in knowledge and stigmatising attitudes among mental health professionals (MHPs; (Whittle et al., 2018)), highlighting the need to provide staff training (Woodward and Halls, 2009) to improve attitudes, as well as skills and knowledge of intellectual disabilities amongst MHPs (Rose et al., 2013).

There has been an increased interest in using qualitative methods in the field of intellectual disability to explore subjective experiences among different groups. For example, parents of people with intellectual disabilities have shared their views and experiences of interacting with professional staff (Doody et al., 2018), people with intellectual disabilities have related their experiences of services received (Ferguson et al., 2010) and of treatment (Evans and Randle-Phillips, 2020; Lewis et al., 2016), and support staff have described their experiences of taking care of people with intellectual disabilities in a residential setting (Ćwirynkała et al., 2017).

Qualitative research involving healthcare professionals has identified their perspectives about general (physical) healthcare services and their experiences working with people with intellectual disabilities. Themes found amongst healthcare professionals are related to the service delivery, organisational work culture, level of knowledge and competency which have an impact on the care quality (Chapman et al., 2017; Morin et al., 2018; Ouellette-Kuntz et al., 2003; Wilkinson et al., 2012). There has been little research on the experiences of MHPs providing mental health services for people with intellectual disabilities, highlighting the necessity to further explore their experiences and the challenges they experience in providing mental health services to people with intellectual disabilities which can lead to improvements in the quality of services for this population.

So far there has been no qualitative review of the experiences and perspectives of MHPs to understand the positive or negative aspects of their work with this specific client population. Research involving MHPs has primarily used quantitative methods to examine knowledge, skills or perceptions of people with intellectual disabilities without exploring personal experiences of working with this client group. The quantitative research findings have not provided much insight into how MHPs' experiences affect their working practice or how they identify their roles and the services they provide for people with intellectual disabilities (Pelleboer-Gunnink et al., 2017; Werner and Stawski, 2012). Qualitative research can complement the quantitative findings by exploring experiences and attitudes of MHPs (Mays and Pope, 2000). Collating and synthesising qualitative findings is becoming increasingly common and offers a rich source of easily accessible and clinically relevant information that may be used to inform policy makers and ultimately improve service delivery (Mays et al., 2005).

## Aim of the review

The purpose of this review is to combine and analyse data from qualitative studies that report on the experiences of MHPs providing services to people with intellectual disabilities and mental health problems. This paper systematically reviews recent qualitative research on the experiences

**Table 1.** List of search terms.

Attitudes	Intellectual Disabilities	Mental Health	Professionals
Attitu*	Intellectual disabili*	Mental health illness*	Staff
OR	OR	OR	OR
Beliefs	Learning disabili*	Psychiatr*	Therapis*
OR	OR	OR	OR
Perception	Mental retardation	Challenging behav*	Nurs*
OR		OR	OR
Experience		Dual diagnos*	Psych*

of MHPs working with people with intellectual disabilities by searching and collating the evidence to answer the following questions:

1. How do MHPs experience their work of providing services to adults with intellectual disabilities and mental health problems?
2. What are the challenges and facilitating factors that MHPs encounter which affect the care and treatment of adults with intellectual disabilities?

## Method

### Search strategy

A systematic search was carried out in 30 June 2020 to identify peer-reviewed articles published between 2006 and 2020 using the electronic databases PubMed, OVID PsychINFO, ProQuest, CINAHL, MEDLINE, PsyARTICLES and ScienceDirect. Past reviews included studies before 2006 and hence, the current review focuses on more recent studies which were published after the adoption of United Nations Convention on the Rights of Persons with Disabilities in 2006.

Table 1 lists the search terms chosen based on reading relevant literature and were combined to obtain the results of the literature search. Research has found that challenging behaviour is the most pronounced feature of mood disorders in people with intellectual disabilities (Hurley, 2008), and there are associations between people with intellectual disabilities having behavioural problems displaying symptoms of psychiatric disorders (Myrbakk and von Tetzchner, 2008). Hence, the term challenging behaviour is regarded in the paper as a symptom of mental health problems and is included in the search.

Table 2 shows the inclusion and exclusion criteria that were used to evaluate and select the studies. The first author carried out the screening of the articles and the screening stage was verified by the second and third authors who ensured that relevant studies met the criteria.

### Extraction of data for meta-synthesis

A type of meta-synthesis named meta-ethnography (Noblit and Hare, 1988) was used as it was deemed to be the most appropriate way of extracting and analysing reported themes across the qualitative studies whilst maintaining the integrity of the primary data. The synthesis was conducted at the level of themes rather than quotes, with themes reported in the included studies being used to develop the overarching themes presented in this review. The first author (JE) first read the

**Table 2.** Inclusion and exclusion criteria for qualitative review.

Inclusion Criteria	Exclusion Criteria
Sample consists of MHPs including medical staff, nurses, therapists, psychologists and social workers	Residential staff or support staff
Must explore the experiences of MHPs working with adults with intellectual disabilities and mental health problems	Describes non-adult mental health services
English language qualitative studies	Exclude review articles, commentaries, book chapters or case studies

included articles and extracted the key themes reported in each paper. He then identified patterns and connections across the themes, grouping them into relevant categories. The first author's views and interpretations were shaped by his profession as a clinical psychologist with background experience of working with people with intellectual disabilities. He was aware of his own experiences and kept a reflective journal during the analytical process and aimed to keep an open mind to minimise potential biases. He engaged in regular discussions and supervision with the second and third authors (JR and BSK) to carry out third order interpretations and develop superordinate themes for each relevant category. Lastly, the superordinate themes were arranged and labelled to form an overall narrative that answered the research questions, illustrated with relevant quotes from the studies.

## Results

A total of 1196 papers was yielded after the systematic search. These publications were screened according to the relevance of title and abstract as well as removing the duplicates, which left 135 papers. From these, the abstracts of these 135 papers were read and 82 articles were removed after failing to meet the inclusion criteria. The main text of the remaining 53 papers were read and 39 papers failed to meet the inclusion criteria, leaving 14 studies for quality assessment and review.

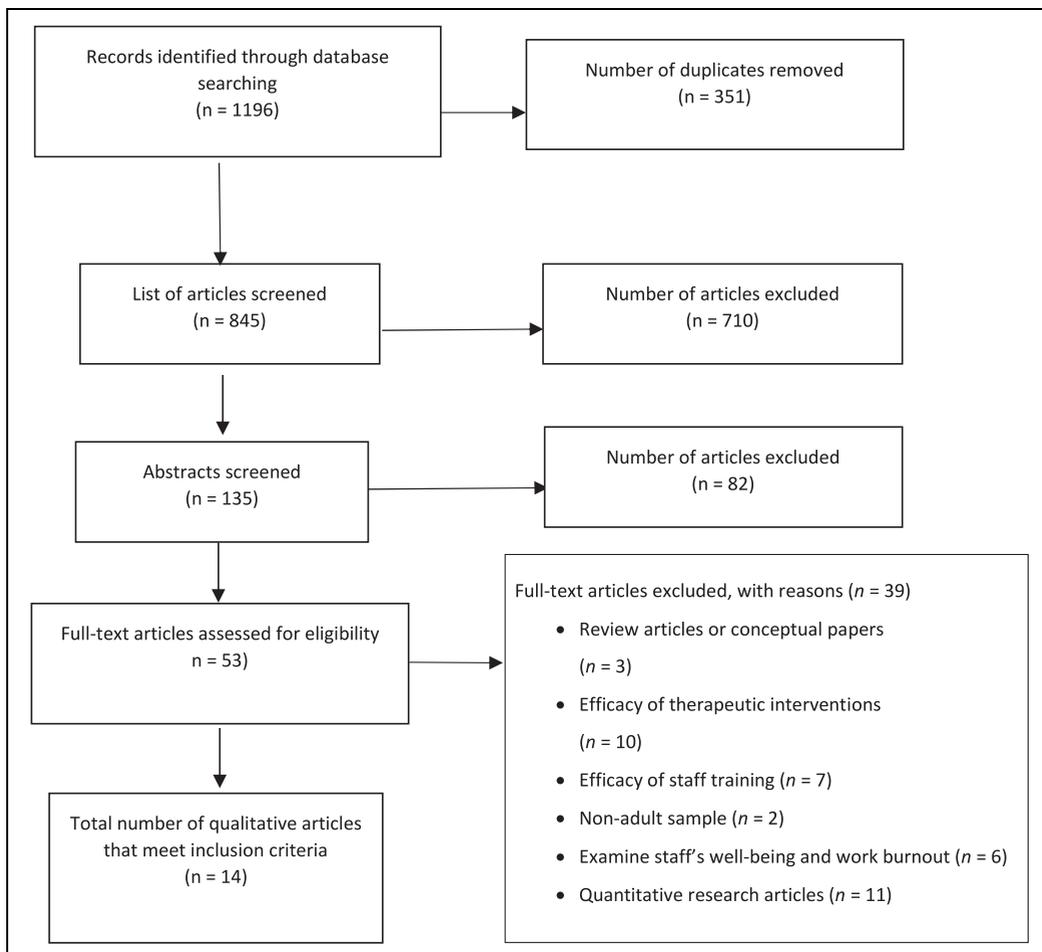
The references of publications were examined to identify additional studies that met the inclusion criteria. None were identified resulting in a final total of 14 studies. Figure 1 shows the flow diagram of the selection process for the review.

### *Study characteristics*

A summary of the papers reviewed detailing the characteristics, findings, strengths and limitations is presented in Table 3. The studies included in this review will be referred to by the numbers allocated in Table 3.

Five of the studies used semi-structured interviews (4, 7, 8, 12 and 14), three studies used a mix of focus groups and semi-structured interviews (2, 9 and 10) and four studies used solely focus groups (1, 3, 5, 13). The remaining two studies (6 and 11) used free association narrative interviews. Most of the studies provided additional information on the questions used to guide the interviews (1, 2, 3, 8, 9, 10, 11, 13 and 14).

The most common qualitative approach utilised by seven studies was thematic analysis (4, 5, 7, 9, 11, 13 and 14), followed by Interpretative Phenomenological Analysis (10 and 12), content analysis (4), thematic analysis with a psychodynamic theoretical framework (6), systematic text condensation (8), grounded theory (1) and two did not specify any approach (Studies 2 and 3).



**Figure 1.** Flow diagram of the qualitative review.

The sample sizes of the studies ranged from 5–44 (median = 13) and included 196 MHPs in total. Studies 6, 7, 11, 12 and 14 recruited nurses ( $n = 50$ ). Studies 8 and 13 recruited psychologists ( $n = 9$ ) and general practitioners ( $n = 10$ ) respectively. The rest of the studies employed a mixture of MHPs including psychiatrists ( $n = 5$ ), nurses ( $n = 42$ ), psychologists ( $n = 12$ ), medical social workers ( $n = 20$ ), speech therapists ( $n = 3$ ) and occupational therapists ( $n = 4$ ).

### *Quality assessment tool*

The quality of studies was evaluated and critically appraised by adapting the checklist from Cesario et al. (2002) and Mays and Pope (2000). Combining the two assessments provides more rigour for the assessment of the quality of the papers and allows the studies to be scored.

The checklist consists of 10 criteria and each criterion can be given a maximum score of 3 points. The scores across the 10 criteria are added to give an overall total score (see Table 3). The

**Table 3.** Summary of qualitative studies (in chronological order).

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations	Quality Assessment score
1	Rose et al. (2007) United Kingdom	To examine the views of MHPs working in intellectual disability and mental health services	Focus group	Grounded theory	29 staff members (20 females, 9 males) 21 MHPs had professional qualifications (15 mainstream staff, 10 specialist staff) Five nurses, one psychiatrist, eight psychologists, one occupational therapist, one speech therapist	<p><b>Definitions of mental health and learning disabilities</b> Diagnostic overshadowing, communication difficulties, what constitutes a mental health diagnosis?</p> <p><b>Staff competence and emotions</b> Feelings of inadequacy, training needs identified, feelings of intimidation, choosing to specialise in intellectual disability field</p> <p><b>Current service delivery issues</b> Boundary issues, workload issues, medication or therapy, service user integration</p> <p><b>Future service deliver issues</b> Specialist of generic services, need to maintain expertise, current generic services inadequate to incorporate this client group</p>	<p>Details of sample characteristics</p> <p>Details of the questions provided</p> <p>Independent analysis by multiple researchers</p>	<p>No reference or details regarding data saturation or reflexivity process</p> <p>Lacked description of techniques to establish credibility and trustworthiness of findings</p> <p>Lacked information regarding audit trail</p>	20
2	Lunsky et al. (2008) Canada	To identify the issues and concerns dealing with people with intellectual disabilities and mental health problems when they are admitted to emergency department (ER) in the hospital	Semi-structured interviews, focus groups	Content/thematic analysis?	44 hospital staff, including psychiatrists and psychiatry residents, nurses, social workers, and other crisis workers—allied health professionals (no information about the breakdown)	<p><b>Description of Client Population</b> Issues that people with intellectual disabilities and mental health problems faced that led him to visit ER: frequency of visits, time spend working with them during consultation and type of treatment used</p> <p><b>Barriers—Challenges</b> Lacked knowledge and experience to work with this population, lack of understanding in the mental health issues and services that they can refer them to in the communities, difficulties to communicate with caregivers and other service providers</p> <p><b>Directions for Intervention</b> Having a less distressing place in the ER, improving interagency communication, having a resource lists, provide training to staff and caregivers</p>	<p>Detailed methodology with audit during data collection</p> <p>Explanation provided regarding the development of questionnaire</p> <p>Wide range of healthcare professionals sampled</p>	<p>Lack of details regarding the analysis</p> <p>Lacked details of the sample characteristics</p> <p>Unclear qualitative theoretical framework used</p> <p>Lack discussion of implications in the discussion section</p>	17

(continued)

Table 3. (continued)

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations	Quality Assessment score
3	Hemmings et al. (2009) United Kingdom	To compare the views of service users, carers and MHPs regarding the community services or support needed by people with intellectual disabilities and psychosis	Focus group	Content analysis (?)	Five specialist professionals (two females, three males with a mean age of 38.2). Two psychiatrists, one nurse, one psychologist and one occupational therapist The rest are carers and service users not included in the review	<b>Staff</b> Need training to increase competency <b>Treatment or interventions</b> Using and adapting various interventions to meet service users' needs, communication with service users to know more about their needs <b>Characteristics of service users</b> May require more intensive services, complex care required for high-risk service users <b>Intensive service components</b> Lack of clarity between specialist vs generic mental health services, lack of experience from professionals treating people with intellectual disabilities and psychosis <b>Reasons people with intellectual disabilities turn to using illicit substances</b> Sub themes of vulnerability, loneliness <b>Assessment and treatment</b> Lack of formal assessment and protocols for intervention, unable to adapt interventions to engage with them <b>Skills and knowledge</b> No further education or specific training working with this population <b>Risk factors</b> Identify factors that can increase the likelihood of the person with intellectual disabilities developing mental health problems <b>Resilient/protective factors</b> Identify factors that increase the self-esteem of person with intellectual disabilities through promoting skills to help them cope with life demands <b>Barriers to accessing healthcare</b> Improve level of access for people with intellectual disabilities to seek mainstream healthcare services	Clear details on the methodology Participants' characteristics were provided Lacked details on the analytic process Lacked details in describing the credibility and validity of the findings Possible researcher biases during analysis	Unclear on the choice of qualitative methodology used Lacked details on the analytic process Lacked details in describing the credibility and validity of the findings Possible researcher biases during analysis	13
4	McLaughlin et al. (2009) United Kingdom	To obtain the experiences and perceptions of MHPs working with people with intellectual disabilities and substance abuse and how their needs could be better met	Semi-structured interviews	Content analysis	13 staff (5 nurses and 3 social workers in intellectual disability settings, 5 mainstream staff) No information about age or experience		Use of multiple researchers in analysis Clear details on identifying the topics for discussion Showed how the interview questions were developed	Lower response rate No discussion on the implications of the findings Lacked details on data saturation or reflexivity process	16
5	Taggart et al. (2010) United Kingdom	To explore MHPs' knowledge and perceptions of caring for women with intellectual disabilities and mental health problems	Focused Group Interviews	Thematic content analysis	32 professionals (7 men and 25 women with age range from 26 to 57 years) 15 nurses, 10 social workers, 2 psychiatrists in specialist mental health settings The others were support workers		Details of audit trail Analysis by different research and independent expert Clear objectives	Limited response from participants Lack details in implications of the findings	22

Table 3. (continued)

No	Author (Year and country)	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations	Quality Assessment score
6	Scorey et al. (2012) United Kingdom	To understand MHPs' accounts of their work with people with intellectual disabilities and mental health needs using psychoanalytical analysis	Free association interview	Psycho-dynamic analysis	Six nurses and two nursing assistants (three females and five males aged between 20-50s) No other information was provided	<p><b>Emotional reactions</b> Negative experiences feelings, sense of powerlessness, feelings of uncertainty</p> <p><b>Organisational issues</b> Little training or experience working with people with intellectual disabilities, lack of available manpower, difficulty managing patients with varying needs</p> <p><b>Patient issues</b> Perceived being targeted by patients, such as emotionally and physically attacked</p> <p><b>Coping strategies</b> Seeking to understand the reason behind their behaviour, displacement of negative emotions onto other things</p> <p><b>Anticipation of violence</b> Constant potential for violence, anticipating violence to occur, feelings of distressed due to constant threat of violence</p> <p><b>Emotional response of anxiety to violence</b> Feelings of anxiety, fear and vulnerability, stressed and scared following exposure to violence</p> <p>Perceived loss of control over their emotions when they became angry</p> <p><b>Normalisation of violence</b> Repeated exposure of violence becomes part and parcel of the job</p> <p><b>Social support</b> Discuss with other colleagues as a way to cope after violent incidents Reflect with colleagues how future incidents can be prevented</p> <p><b>Extrinsic support</b> Lack of support from management to address staff's well being Perceive that the level of violence is accepted by management</p>	<p>Lack details in data analysis and audit trail</p> <p>Details of sample were not provided</p> <p>Inconsistent procedures applied to participants</p>	20	
7	Campbell (2013) United Kingdom	To explore the experiences of nurses making sense of the violent incidents when taking care of people with intellectual disabilities and challenging behaviours	Semi-structured interviews	Thematic Analysis	Six registered nurses (no further details provided)	<p><b>Anticipation of violence</b> Constant potential for violence, anticipating violence to occur, feelings of distressed due to constant threat of violence</p> <p><b>Emotional response of anxiety to violence</b> Feelings of anxiety, fear and vulnerability, stressed and scared following exposure to violence</p> <p>Perceived loss of control over their emotions when they became angry</p> <p><b>Normalisation of violence</b> Repeated exposure of violence becomes part and parcel of the job</p> <p><b>Social support</b> Discuss with other colleagues as a way to cope after violent incidents Reflect with colleagues how future incidents can be prevented</p> <p><b>Extrinsic support</b> Lack of support from management to address staff's well being Perceive that the level of violence is accepted by management</p>	<p>Clear literature background</p> <p>Appropriate methodology to address the research question</p> <p>Appropriate details of procedure</p> <p>Appropriate use of quotes in the results section</p> <p>Strategies were put in place should participants become distressed</p>	<p>Sample size can be improved</p> <p>Lacked details regarding data saturation and participants' demographics</p> <p>No details regarding reflexivity or audit trail</p> <p>Information about the questions were not provided</p>	19

(continued)

Table 3. (continued)

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations	Quality Assessment score
8	Fredheim et al. (2013) Norway	To explore the experiences, attitudes and perceived role and competence of general practitioners providing health services to people with intellectual disabilities and mental health problems	Semi-structured interviews	Systematic text condensation	Practitioners (GPs) Seven males and three females ranging from 41 to 64 years old	<p><b>Basic for decisions</b> Limited training, knowledge of the individuals' background and continuity in the physician-patient relationship provides best service</p> <p><b>Consultations</b> Seeing the person at home, having someone who knows the person be present during visits</p> <p><b>Treatment</b> Lack of confidence that a specialist would do a better job, fears specialist health services would reject the referral</p> <p><b>Evaluation and continuing treatment</b> Challenges in reviewing medication, unsure of attending interdisciplinary meetings</p> <p><b>Compliance vs challenge</b> Women are more likely to comply while men have a tendency to challenge</p> <p><b>Vulnerability</b> Women are more vulnerable to abuse while men are more likely to experience addictions</p> <p><b>Expression of emotion</b> Women are more likely to express their anxieties and talk more about their mental health problems</p> <p><b>Differences in staff treatment in men and women</b> Equality, same-sex support, boundaries</p> <p><b>Desirable staff qualities</b> Being interested, communication styles and techniques, competence promoting support, awareness of link between past, present and future</p> <p><b>Good quality services</b> Prevention, Regular reviews and liaison, working with care, looking after staff, staff training/supervision, Interface between services</p>	Provides detailed summary of participant characteristics Discussion of implications of clinical practice Provide information about the questions used during the interview	Lacked details on the choice of theoretical framework for analysis No reference to data saturation Lacked information about credibility checks	17
9	Stenfort-Kroese et al. (2013a) United Kingdom	To investigate MHPs and service users' views of gender differences in cause and presentation of mental health problems in people with intellectual disabilities and whether they are any differences in the way the current services respond relating to gender	Focused Group and semi-structured Interviews	Thematic Analysis	Focus Group 16 staff including healthcare professionals (10 females and 6 males) 2 nurses, 1 social worker, 3 psychologists and 1 counsellor. The rest are support staff Interviews 10 healthcare professionals (7 females and 3 males with average age of 43), 5 nurses, 4 social workers and 1 psychologist	<p><b>Expression of emotion</b> Women are more likely to express their anxieties and talk more about their mental health problems</p> <p><b>Differences in staff treatment in men and women</b> Equality, same-sex support, boundaries</p> <p><b>Desirable staff qualities</b> Being interested, communication styles and techniques, competence promoting support, awareness of link between past, present and future</p> <p><b>Good quality services</b> Prevention, Regular reviews and liaison, working with care, looking after staff, staff training/supervision, Interface between services</p>	Provided clear details on methodology Clear aims with support from relevant literature Details of audit trail and analysis by multiple researchers	Lacked discussion on the reflexivity during analytic process	25
10	Stenfort-Kroese et al. (2013b) United Kingdom	To explore experiences of MHPs and service users regarding the provision of mental health services and suggestions to improve the delivery of services	Focused Group and semi-structured interviews	Interpretative Phenomenological Analysis	Focus Group 16 staff including healthcare professionals (10 females and 6 males) 2 nurses, 1 social worker, 3 psychologists and 1 counsellor. The rest are support staff Interviews 10 healthcare professionals (7 females and 3 males with average age of 43), 5 nurses, 4 social workers and 1 psychologist	<p><b>Expression of emotion</b> Women are more likely to express their anxieties and talk more about their mental health problems</p> <p><b>Differences in staff treatment in men and women</b> Equality, same-sex support, boundaries</p> <p><b>Desirable staff qualities</b> Being interested, communication styles and techniques, competence promoting support, awareness of link between past, present and future</p> <p><b>Good quality services</b> Prevention, Regular reviews and liaison, working with care, looking after staff, staff training/supervision, Interface between services</p>	Provided clear details on methodology Clear aims with support from relevant literature Details of audit trail and analysis by multiple researchers	Limited discussion on the limitations of the findings Purposive sample	25

(continued)

Table 3. (continued)

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations	Quality Assessment score
11	Capri and Buckle (2015) South Africa	To examine the challenges faced by nurses taking care of people with intellectual disabilities and mental health problems and suggestions to address these care challenges	Free association narrative interview	Thematic Analysis	13 females and 3 males nurses with a working experience ranging from 3 to 30 years	<p><b>Relational interaction</b></p> <p>Fulfillment, reciprocity, meaningfulness, pride in their work, noble self-perception</p> <p><b>Care burden</b></p> <p>Difficult to care for, trying to reduce self-injury behaviours, encountered episodes of violence and assault, feelings of fear, constant vigilance, powerlessness, ward as work environment, lack stimulating work, invasion of personal boundaries, adjusting to work environment, negative stigma working in this field</p> <p><b>System fatigue (organizational factors)</b></p> <p>Heavy workload, mental and physical depletion, critical staff shortages, chronic staffing issues, staff inadequacy</p> <p><b>System fatigue (lack of organizational support: little care for the carer)</b></p> <p>Feeling abandoned, exploited, unacknowledged, devalued, marginalized, scapegoated, judged, unheard regarding patient care requirements, embattled, disregarded, disrespected, unappreciated by other MHPS, emotionally exhausted, depersonalized</p> <p><b>Infantilising dynamic of care</b></p> <p>Treating people with intellectual disabilities as children, mother-child bond, lack empowerment in people with intellectual disabilities, inadequate preparation during formal training, limited opportunities for further training</p> <p><b>Resources for coping</b></p> <p>Internal and external sources, taking leave, designated counselling, reliable reciprocated and functional support</p>	<p>Possible gender biases in participants' responses</p> <p>No details on how the translation process during the transcription of data</p>	24	

(continued)

Table 3. (continued)

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations	Quality Assessment score
12	Lee and Kiemle (2015) United Kingdom	To examine the experiences of nurses working with people with intellectual disabilities and personality disorder	Semi-structured interviews	Interpretative Phenomenological Analysis	Two male and seven female qualified intellectual disability nurses with a mean age of 42 and worked for an average of 9.3 years. Work experience ranged from 14 months to 2 years	<p><b>Disorder overriding disability</b> Negative traits attributed to mental health problems, difficulty forming meaningful therapeutic relationships, need for structure, challenges attributed to mental health problems</p> <p><b>Resilience</b> Focus on the positive, emotionally distant from clients, difficulty to care for them at times</p> <p><b>Seeing the person behind the label towards label</b> Consequence of label, gender differences in attribution of behaviours</p> <p><b>Knowledge</b> Having lack of training, importance of knowledge, level of understanding increased over time</p>	<p>Clear references to credibility and triangulation checks</p> <p>Themes are well-described with relevant quotes</p> <p>Details about the reflexive practices and audit trails</p>	<p>Brief details of sample</p> <p>Details of the interview schedule were not provided</p> <p>Unclear whether the participants were debriefed</p>	26
13	McNally and McMurray (2015) United Kingdom	To investigate the experiences of psychologists towards people with intellectual disabilities accessing mainstream mental health services	Focus groups	Thematic Analysis	Two groups of participants – 4 psychologists in mental health team and 5 psychologists in intellectual disability team (no further information is provided)	<p><b>Themes from mainstream mental health services</b> Lack of appropriate structure and resources, overwhelming service demands, developing specialist mental health service</p> <p><b>Confidence in ability</b> Feelings of anxiety, lack experience, need for supervision</p> <p><b>Resistance to change</b> Limited outcomes in mainstream services, preference for people with intellectual disabilities to access specialist services, wants more autonomy in their work with people with intellectual disabilities</p>	<p>Use of appropriate methodology</p> <p>Applying credibility checks during the analysis phase</p>	<p>Lacked information regarding missing data and data saturation</p> <p>Lacked details about audit trails</p> <p>Lacked description of participants' characteristics</p> <p>Possible biases from researchers during analysis</p>	17

(continued)

Table 3. (continued)

No	Author (Year and country)	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations	Quality Assessment score
14	Taua et al. (2017) New Zealand	To explore how nurses utilize their skills caring for people with intellectual disabilities and mental health problems in inpatient mental health settings	Semi-structured interviews	Thematic Analysis	13 nurses (9 females and 4 males with average age of 45 and 18-46 years of work experience)	<p><b>Themes from specialist intellectual disability</b></p> <p><b>Future thinking</b> People with intellectual disabilities having a right to access mainstream services, help people with intellectual disabilities to understand their rights, providing clear pathways for them to access mainstream services</p> <p><b>Protection</b> Being protective towards people with intellectual disabilities, perceive that mainstream staff does not want to work with this population</p> <p><b>Pessimism</b> Mainstream mental health service not willing to make necessary adjustments</p> <p><b>Clarification around mental health and intellectual disability</b> Influence of diagnostic shadowing</p> <p><b>Contextualizing behaviour</b> Having the skill to recognise challenging behaviour, manage risk-related issues and provide opportunities for people with intellectual disabilities to learn how to manage their behaviour</p> <p><b>Communication</b> Having effective communication strategies when interacting with person with intellectual disabilities</p> <p><b>Confidence to care</b> Having an in-depth knowledge improves staff's confidence to care for person with intellectual disabilities</p> <p><b>Time</b> Having adequate time to work effectively to support people with intellectual disabilities as well as gaining additional experience</p>	<p>Details of sample characteristics</p> <p>Include details of interview schedule</p> <p>Clear methodology and aims</p>	<p>Lack details of audit trail</p> <p>Sampling response bias</p> <p>Lack reflexivity</p> <p>Nothing was mentioned about informed consent and confidentiality of the data</p>	18

**Table 4.** Synthesis of themes.

Main themes	Studies that contribute to the themes/sub-themes	Sub themes
1. Understanding the person	1, 2, 3, 4, 5, 10, 12, 13 and 14	i. Identifying mental health problems ii. Complexity of mental health problems
2. Relational Interaction	1, 4, 8, 10, 11 and 14 1, 2, 4, 6, 7, 8, 10, 11, 12, 13 and 14 2, 6, 7, 11, 12	i. Communication ii. Emotional reactions iii. Care burden
3. Organisational factors	1, 2, 4, 6, 7, 9, 10, 11 and 13	i. Perceived lack of support ii. Recommendations to improve services

first author carried out the the quality assessment which was verified by the second and third authors.

Four of the studies (9, 10, 11 and 12) stood out for having attained a high quality ratings (24+). These studies have a detailed background literature, clearly defined hypotheses, appropriate explanation of the use of the methodology to collect the interviews and a detailed explanation of the analysis process to develop the themes.

The majority (N = 9) of the studies were judged as being of a lower quality as they did not provide a detailed description of the audit trail or explained the rationale for choosing the particular epistemological stance for analysis.

Study 3, with the lowest quality score of 13, lacked a detailed description of the sample size, objectives and aims of the study. There was no information regarding the type of analysis used and lacked details about how the data were collected.

### *Meta-synthesis findings*

Table 4 shows the three main themes that were identified which were 1) Understanding the person; 2) Relational Interaction between healthcare professional and the service user and 3) Organisational factors. The second theme consists of three subthemes while the others consist of two subthemes.

The quotations from the MHPs in the studies are presented in italics whereas the quotations from study authors are not.

#### *Theme 1: Understanding the person*

This theme describes how MHPs develop an understanding of the adult with intellectual disabilities in a holistic manner while at the same time identifying the individual's mental health problems during the assessment phase.

*Sub-theme 1: Identifying mental health problems.* MHPs recognised that adults with intellectual disabilities had a higher prevalence of mental health problems and that their family members often did not seek help until they were unable to manage. MHPs noted that the behaviours of the person with intellectual disabilities became the main focus of treatment where family members looked for a cure to eliminate the behaviours or transfer the burden of care to them,

They [the carers] bring the patient to the ER looking for a miracle pill or wanting the hospital because they can't cope. (Lunsky et al., 2008: 449)

MHPs acknowledged that their colleagues sometimes attributed the behaviours to the intellectual disabilities diagnosis and failed to recognise that these behaviours might represent underlying mental health problems that require treatment,

I think people just look at it all together really, they think it's just challenging behaviour, they don't think about the mental health issues. (Rose et al., 2007: 55)

Other MHPs recognised that the mental health problems in adults with intellectual disabilities may be manifestations of other problem behaviours, such as substance abuse or self-harm, caused by previous exploitation, sexual abuse or due to social circumstances such as feeling a sense of loneliness with a lack of adequate social support,

Again a lot of physical problems, maybe presenting to casualty, overdosing, self-harming, just self-neglect again, one or two of them are very vulnerable and I feel that a lot of them have maybe been exploited, financially and query sexually. (McLaughlin et al., 2009: 136)

MHPs reflected that they needed to spend time '*getting to know each client on an individual basis*' (Stenfert Kroese et al., 2013b: 6), trying to identify behavioural issues and assess whether they were mental health related or due to the individual's intellectual disabilities,

It's a matter of trial and error... it's important to take the time to listen, taking the time to observe, trying things, failing... learning from those mistakes. (Taua et al., 2017: 636)

Likewise, MHPs described the assessment process as requiring extensive resources and time, especially when there were challenges in obtaining relevant information before they could formulate and carry out their treatment plan.

This was particularly difficult for MHPs working in mainstream settings because of the high service demands, '*We're obviously swamped and the more people we can keep out the better*' and the lack of resources available in mainstream services, '*...you really do need much more resources... where would you even get that...?*' (McNally and McMurray, 2015: 355).

The benefits of having extra time during the assessment helped MHPs to conduct a comprehensive assessment of the person with intellectual disabilities to have a holistic understanding of the person as a whole,

They've all got their own special qualities, when you actually see the person, not the personality disorder and not the learning disability. (Lee and Kiemle, 2015: 243)

**Sub-theme 2: Complexity of mental health problems.** This sub-theme describes the complexity of mental health problems that MHPs encountered, the underlying risk factors and the challenges their clients face that contribute to their negative cognitions and feelings, and poor coping strategies,

I have a few women who definitely use alcohol as a coping mechanism. They struggle with the expectations placed on them and they don't see themselves as meeting these expectations, therefore they are depressed and lonely, using the alcohol to give them a reprieve and a release from feeling that way. (Taggart et al., 2010: 95)

Lee and Kiemle (2015) identified feelings of frustration that the MHPs sometimes ‘*struggled to get past*’ (p. 249) when they were unable to make any progress working with adults with intellectual disabilities which led them to conclude that the mental health problems in this population are negative personality traits or attributions which are ‘*fixed and cannot be improved*’ (p. 249).

MHPs observed that their clients’ mental health problems were often not addressed due to their intellectual disabilities,

Most people that we see have a learning disability have a mental health problem, but actually, when I think, a lot of them don’t have a diagnosis. (McNally and McMurray, 2015: 357)

Given the complexity of mental health problems in adults with intellectual disabilities, MHPs agreed that psychotropic medication is often used as ‘*the first line [treatment]*’ (Rose et al., 2007: 56). MHPs sometimes observed that their colleagues lacked the knowledge of non-pharmacological treatment, ‘*... what is the level of understanding for CBT...?*’ (Study 1, p. 56) and only offered medication without any psychological intervention, ‘*... there is no counselling, there is nothing, basically just medication and that’s it*’ (Taggart et al., 2010: 96).

## **Theme 2: Relational interaction**

This second theme relates to how MHPs view their therapeutic relationships with their clients as a ‘deeply emotional, intimate’ (Kittay et al., 2005: 444) and finding a sense of fulfilment when engaging with them during the intervention process but also reporting on negative emotions.

**Sub-theme 1: Communication.** MHPs described challenges in communicating with people with intellectual disabilities and mental health problems and in establishing therapeutic relationships with them,

The hardest part is communication, getting yourself across in the right manner. (Rose et al., 2007: 55)

MHPs in Capri and Buckle (2015) attuned themselves to the communication needs of people with intellectual disabilities through ‘*reading body language(s) or by familiarity with their personality*’ (p. 176). It was noted that the development of rapport does not need to solely rely on the use of verbal communication, other forms of non-verbal communication can also be used,

A lot of experience I had was... using pictures and diagrams and just learning to actually think quite laterally about how can you explain things in quite a basic way... explain something in a way that is empowering and not patronizing. (Tuaa et al., 2017: 634)

Their relationships with clients sometimes affected the MHPs emotionally when they viewed themselves as a parental figure, ‘*I grew attached quickly... I’m a mommy at work; I came to love them, they are my children...*’ (Capri and Buckle, 2015: 176) and became sad when their client was discharged from the services,

We have to prepare them for the community, but when they go... I am very sad... I have to walk away. (Capri and Buckle, 2015: 176)

**Sub-theme 2: Emotional reactions.** All of the studies, with the exception of 3, 5 and 9 highlighted the emotional reactions that MHPs experienced when working with adults with intellectual disabilities and mental health problems. MHPs in Capri and Buckle (2015) shared that they ‘*feel proud*’ and

'enjoy doing the work' despite acknowledging that 'it is not easy working' with this population, reflecting a 'noble self-perception' (p. 173) of providing services and care to someone with high care needs and mental health problems.

MHPs in other studies reported on the fluctuating emotions,

It's one of the hardest jobs in the world. And it was like a roller coaster ride. Erm, and sometimes you'd find it really overwhelming. (Lee and Kiemle, 2015: 242)

Feelings that MHPs reported included anger, anxiety and stress when exposed to violence,

Stressed and quite scared sometimes, sometimes angry that we should be exposed to this – it is a mixture really. (Campbell, 2013: 44)

In addition, feelings of intimidation and being scared, '*It's still quite scary*' (McNally and McMurray, 2015: 355), were reported when MHPs lacked confidence, often due to inexperience, training and knowledge,

I don't know whether it's actually training but some kind of awareness sessions or some to staff in feeling less intimidated maybe because I think a lot of it is that they [the staff] feel intimidated. (Rose et al., 2007: 56)

At times, MHPs expressed feelings of vulnerability and inadequacy as a result of emotional fatigue, often exacerbated by repeated exposure to violence or increased workload that affected the therapeutic relationship with clients,

It makes me feel, not all the time but it does make me feel vulnerable and sometimes I must admit I have actually thought 'what am I doing here', 'why am I doing this' and then I think about it. (Campbell, 2013: 44)

Sometimes, MHPs experienced feeling alone because of their lack of experience, especially when faced with challenges and no clear avenues to seek help,

I feel really alone on this topic with these patients. I don't really know what to do. (Fredheim et al., 2013: 5)

**Sub-theme 3: Care burden.** MHPs described having negative experiences of being verbally or physically targeted, affecting their sense of motivation to continue working in this field. Some expressed caution when they talked of developing therapeutic relationships and preferred to remain emotionally distant from some of their clients,

The symptoms, if you like, of personality disorder make you a lot more wary of developing a relationship, yep, erm, yea again, you're kinda a lot more suspicious! (Lee and Kiemle, 2015: 242)

The threat of violence was something that MHPs had concerns about, knowing that there was always the potential for violence when working with some clients,

Every day when you walk on a shift or when you walk onto the unit until you know what is actually happening you need to be aware that it [violence] can happen at any time . . . (Lunsky et al., 2008: 43)

Working with some people with intellectual disabilities and complex mental health problems was described as a tiring and frustrating experience,

It can be quite tiring cos obviously, a lot of the behaviours are repeated, over and over, and that's quite frustrating. It can feel quite hard cos you don't seem to move on from things and move forwards. (Lee and Kiemle, 2015: 241)

Participants viewed themselves as '*weak*' and blamed themselves when their clients made them upset,

She'd also know things that pushed my buttons. . . . that was really tiring, cos she would just be on you and you knew, you'd trip up before she would if you weren't careful 'cos she was that good at it . . . she'd have a subject that she knew I couldn't, I wouldn't, I was weak on and she'd always manage to trip me up . . . . (Storey et al., 2012: 233)

MHPs developed coping strategies to manage stress by focusing on the positive characteristics or resilience traits of the person with intellectual disabilities, '*I try not to be pessimistic . . . and look at it positively*' (Storey et al., 2012: 231) and valued a designated external mental health professional from whom they could seek professional help,

It would have been nice to know that there would be someone . . . if I'm having these feelings that I'm bottling up . . . I can go talk to. We don't have that. (Capri and Buckle, 2015: 177)

There were some who preferred not to discuss any emotional impact or feelings of vulnerability and helplessness because they felt that expressing such feelings was forbidden, '*You're not supposed to say things . . . like that . . .*' (Storey et al., 2012: 233).

### **Theme 3: Organisational factors**

The final theme described the organisational barriers and support that MHPs encountered and their views and recommendations to improve services.

*Sub-theme 1: Perceived lack of support.* This sub-theme describes the lack of support in the workplace. They identified an increased workload as a result of unnecessary administrative procedures, staff shortages which affected their morale, and stress when they were unable to do their job satisfactorily (Storey et al., 2012: 232; Stenfert Kroese et al., 2013b: 9). They agreed that heavy workload and long working hours led to emotional fatigue, '*Sometimes it feels so overwhelming*' (Capri and Buckle, 2015: 174), often resulting in stress-related symptoms and leaving them feeling exploited and unappreciated,

You get tired, working long hours, when you get home, you don't really have time for your family, you just want to get in the bath and into bed. (Capri and Buckle, 2015: 174)

Many MHPs reported that their managers did not support them and lacked empathy to address their concerns. For example, managers could be seen as unresponsive to the emotional impact of violence in the workplace, which could increase feelings of powerlessness,

There is sort of a feeling that we are not supported enough because . . . I think management have got this idea that there is a certain threshold/tolerance level for violence in the workplace that has almost

become acceptable. So I often feel . . . we don't get the support that we should be getting. (Campbell, 2013: 44)

Forms of valued support include teamworking and multidisciplinary collaboration with other MHPs. However, they also described the challenges of working with other MHPs when their role and expertise were not always valued, hence perceiving that their opinions were not important enough to be taken into consideration during multi-disciplinary meetings,

Sometimes [the doctors are] very nasty . . . they criticise. The nurse's voice is not always so important unless it's the doctor . . . if it's a nurse who sees there's a need then they won't jump to help you. (Capri and Buckle, 2015: 175)

Further areas of support that MHPs found lacking in their workplace was the lack of training and supervision to improve their clinical practice and increase their knowledge of the dual specialities of intellectual disabilities and mental health. Most MHPs considered additional training to be an important component as part of their job, '*People should have the right training for the job so they can do their job properly*' (Stenfert Kroese et al., 2013b: 9–10).

*Sub-theme 2: Recommendations to improve services.* MHPs talked about the importance of early detection of mental health problems of people with intellectual disabilities. They spoke about the lack of coordination between different services and a lack of knowledge regarding where adults with intellectual disabilities and mental health problems can seek help,

The system is fragmented. We don't know what's out there and it's hard to navigate. (McLaughlin et al., 2009: 450)

There was an agreement among the MHPs that the current mental health services were inadequate and not meeting the needs of people with intellectual disabilities,

I don't think our service is geared up to be sympathetic to a client group that might be struggling with the confidence to actually say, oh yes I could get myself to wherever to see this psychologist on my own . . . (Rose et al., 2007: 57)

Training for MHPs in hospital departments was recommended,

. . . people with intellectual disabilities being placed with [psychiatric] hospital staff that haven't got the knowledge to work with them or might even find it quite frustrating to work with somebody with a learning disability if they haven't done before . . . (Stenfert Kroese et al., 2013b: 11)

In addition, some MHPs considered whether establishing specialist services where they did not exist previously would improve the quality of care for this population while others considered that having a specialised service would go against their right to access mainstream mental health service,

From an equality point of view, it would be difficult to argue anything but that they have a right to access the mainstream adult mental health setting. (McNally and McMurray, 2015: 357)

Existing collaboration between community services, primary healthcare settings and tertiary mental healthcare teams that comprised of MHPs with differing specialities and experiences was seen as a positive way to access appropriate services,

If I wanted to refer a patient with these problems, NN was the person. NN, a psychiatrist with long experience, is easy to turn to, because he provides good answers to my questions. (Fredheim et al., 2013: 5)

MHPs recommended improving accessibility of mainstream services to address social needs,

I think it's about helping them access the generic services especially the housing... and substance misuse and employment. (Hemmings et al., 2009: 26)

There were several suggestions to reduce the barriers to accessing mental health services for adults with intellectual disabilities, e.g. having a '*health promotion literature in a user friendly format*' and a '*resource list of available services, including a website and a 24-hr telephone line*' (Lunsky et al., 2008: 449; Taggart et al., 2010: 97) for family members, and having access to MHPs of the same gender for cases of domestic and sexual abuse (Stenfert Kroese et al., 2013a: 187).

They also recognised the importance of using screening tools to detect early signs of mental health problems so that people with intellectual disabilities can be referred to appropriate services for a more comprehensive assessment and treatment (McNally and McMurray, 2015: 96).

## Discussion

This paper focused on the experiences of MHPs providing services for adults with intellectual disabilities and mental health problems. Findings of the meta-synthesis identified three main themes: (1) understanding the person beyond their diagnoses (2) therapeutic relationship and interactions with people with intellectual disabilities when working with them and lastly (3); organisational barriers and recommendations to improve the mental health services to this population.

MHPs reported that mental health symptoms were sometimes misattributed to their clients' intellectual disabilities and not promptly treated. Reiss et al. (1982) termed this misattribution bias 'diagnostic overshadowing' which may influence the treatment of adults with intellectual disabilities and may lead to negative perceptions or stigmatising attitudes towards them (Jopp and Keys, 2001).

Due to the complexity of presenting problems, MHPs reported taking longer and needing more resources when working with people with intellectual disabilities, which they did not often have, especially when working in mainstream services. As a result, they were at times overwhelmed and MHPs acknowledged that psychotropic medication is often used as the first treatment of choice. Some MHPs may view the mental health problems solely from a medical treatment model perspective and consider the problem to lie with the person with intellectual disabilities for being unable to adjust to their environment (Williams and Heslop, 2005). This may explain the feelings of frustration when MHPs struggle to make progress and lead them to view their clients as untreatable.

Previous studies have explored the effectiveness of training for MHPs to increase their understanding of mental health issues of people with intellectual disabilities and found an increase in their level of confidence and knowledge after attending a teaching programme (Costello et al.,

2007; Mohr et al., 2002). However, these improvements may not be maintained over time due to factors such as repeated exposure to violence and aggression, which may increase their care burden and evoke negative emotional reactions as highlighted in this review. The current findings are consistent with quantitative research conducted with direct care staff which found a positive correlation between negative emotions experienced by staff and severity of clients' aggressive behaviours as well as predicting use of coercive measures to manage these behaviours (Hensel et al., 2014; Knotter et al., 2013).

It is interesting that although MHPs recounted positive experiences, many indicated that they experienced negative emotions and stress that affected their therapeutic relationships with their clients. They also perceived a lack of coping resources in their workplace and insufficient support from managers which exacerbated their stress, leaving them to feel burnt out and unappreciated. A growing body of literature suggests that this is common among MHPs where high levels of stress and burnout negatively affects staff motivation and increases staff turnover (Langdon et al., 2007; Søndena et al., 2015). Frequent exposure to aggressive behaviours has also been found to contribute towards emotional difficulties in MHPs (Hensel et al., 2014).

In the main theme *Relational Interaction*, MHPs understood the importance of building rapport with people with intellectual disabilities. Having a trusting therapeutic relationship (Ramsden et al., 2015) is essential and can only be acquired by working competently over a period of time. The therapeutic relationship is important for people with intellectual disabilities and they identified the ability to build such relationships as a desirable quality that MHPs should possess and only feeling comfortable sharing their emotional difficulties after a genuine working relationship has been established (Lewis et al., 2016; Weiss et al., 2009).

Our findings confirm that more support is required to address the mental and emotional well-being of MHPs working with people with intellectual disabilities and mental health problems (Edwards and Burnard, 2003). Help-seeking behaviours among MHPs are likely to be influenced by their work culture and environment (Chan and Huak, 2004) where there may be a lack of motivation to use appropriate resources for fear of being penalised. Regular supervision sessions and/or stress management interventions for staff are regarded as essential for creating a positive organisational culture. Having an experienced supervisor can help junior staff to cope with work stress and demands (Acker, 2011). Stress management interventions for support staff have been shown to reduce levels of distress, may improve well-being and mitigate negative emotions (Innstrand et al., 2004; McConachie et al., 2014).

There is no clear consensus among MHPs regarding the need for specialist mental health services for people with intellectual disabilities. Some were keen on a specialist mental health service whilst others expressed concerns that this could be viewed as a way of depriving them of the right to access mainstream services. They advocated instead for more resources to adapt mainstream services to become accessible and responsive to the needs of people with intellectual disabilities. One suggestion is for the specialist services to be embedded within community settings or co-located in primary healthcare services to increase the rates of early detection of mental health problems in people with intellectual disabilities and improved access to services and treatments (Ervin et al., 2014; Hemmings et al., 2014). Further research should explore the views of other stakeholders regarding specialist services to inform future commissioning.

There are some limitations of this review which must be noted. The selected studies lacked details to demonstrate evidence of reflectivity and description of audit trails as was highlighted in the quality appraisal. Also, the majority of the studies were carried out in western countries (and 10 of the 14 studies in the UK) where culture, clinical practice and experiences may differ from other parts of the

world, hence the findings may not be generalisable to non-western countries. Moreover, the findings from the meta-synthesis are based on qualitative data that was derived from different participant groups, with different levels of work experience and working in different environments. The themes thus represent the common experiences, emotional reactions and challenges faced and any nuanced differences between the participant groups has not be considered.

### Authors' note

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