

REVIEW

Identifying Training Needs for Mainstream Healthcare Professionals, to Prepare Them for Working with Individuals with Intellectual Disabilities: A Systematic Review

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Background Research suggests there is a high prevalence of physical and mental ill health among individuals with intellectual disabilities and that staff working in mainstream healthcare services lack knowledge, skills and positive attitudes in supporting this client group. This review aimed to locate, extract themes from and evaluate the current literature that had assessed the training needs of mainstream health professionals within this area.

Methods This review utilized a mixed-methods approach, with systematic elements used to locate and evaluate the literature ($n = 13$) and a narrative approach used to explore patterns and themes identified. The search was completed across four databases, using the search terms felt most likely to capture the relevant literature.

Results Three main themes of perceived training need were identified across a range of professional groups: general communication, knowledge/information and profession-specific needs.

Conclusions This review highlights the existing themes of training needs as identified by mainstream healthcare staff. It would appear that it may be possible to produce a core training package, suitable across professions with elements that are profession specific and therefore tailored accordingly. Limitations of the literature are explored within this review, as are recommendations for the directions of future research.

Keywords: intellectual disabilities, staff, training

Introduction

People with intellectual disabilities have poorer physical (e.g. Emerson *et al.* 2009) and mental (e.g. Emerson & Hatton 2007) health than the general population. This is a significant health inequality (e.g. Emerson *et al.* 2009). Emerson & Baines (2010) make the challenging assertion that such inequalities are ‘to an extent, avoidable’. They go on to identify that such inequalities start early in life, continue through into adulthood and are significantly due to the difficulties such individuals face in accessing ‘timely, appropriate and effective health care’ (Emerson & Baines 2010). Improving both access to and equality

of treatment received in primary care services (e.g. General Practice surgeries; Prasher & Janicki, 2002; Glover, Emerson & Evison, 2012) and general hospitals (Mencap, *Death by Indifference*, 2007; Lewis & Sternfert-Kroese, 2010) are vital to improving the health and well-being of individuals with intellectual disabilities. This includes the early detection of physical and mental health related conditions, as well as timely and good quality treatment for more urgent and serious medical conditions. Furthermore, recent developments have begun to see individuals with intellectual disabilities accessing “talking therapies” through mainstream services (Improving Access to Psychological

Therapies; DOH, 2009) which if delivered effectively and by sufficiently trained therapists, could see more individuals with intellectual disabilities accessing such services and therefore an improvement in the mental health of such individuals.

Within the UK, the Equality Act (2010) requires that policies and practices of organizations such as the National Health Service (NHS) do not discriminate against people with disability in their access to a receipt of services. In areas such as mental health, where there has been a history of separate service provision, there is now a broad policy direction in favour of mainstreaming for mental health services for people with intellectual disabilities. For example, this is an aim within the English mental health strategy, *No Health Without Mental Health* (Department of Health; DOH, 2011) and being driven by Care Quality Commission/Monitor standards (Monitor 2013). Although mainstream services are identified as needing to provide services to people with learning disabilities, Emerson & Baines (2010) identify a number of barriers to this including failures to make reasonable adjustments and 'disablist' attitudes to people with intellectual disabilities.

Despite increased attention to meeting the physical and mental health needs of individuals with intellectual disabilities within mainstream healthcare services (DoH 2001, 2009), significant barriers still exist. One particular barrier identified is that mainstream healthcare staff report fewer positive attitudes towards caring for clients with intellectual disabilities, which is suggested therefore to negatively impact upon the quality of care provided to this client group (McConkey & Truesdale 2000; Lewis & Sternfert-Kroese 2010). Negative attitudes are considered to be one of the main barriers to individuals with intellectual disabilities gaining access to equal treatment within mainstream healthcare services. Lewis and Sternfert-Kroese (2010) completed a study with general hospital nursing staff that demonstrated that negative attitudes towards individuals with intellectual disabilities resulted in nurses feeling that they would segregate this client group from others in hospital due to the perceived difficulties in their presentation. Nurses also reported that they would be less likely to complete invasive procedures with such clients, they would be more likely to ask carers to remain with the individual and they would be less likely to spend time explaining treatment plans or ask if a patient was in pain. It is likely therefore that negative attitudes contribute to a number of aspects that ultimately result in barriers to accessing

and receiving high quality health care for individuals with intellectual disabilities.

One of the ways in which the provision of healthcare services for people with intellectual disabilities could be improved is through training healthcare staff in preparation for working with people with intellectual disabilities (Lewis & Sternfert-Kroese 2010). At present, some core professional training curricula do not include practice in working with people with intellectual disabilities (Sweeney 2004). Ensuring that mainstream professionals know both how to provide and how to make health care accessible to clients with intellectual disabilities could have a positive impact on service provision for this client group.

If staff training could play an important role in improving health care for individuals with intellectual disabilities, getting the training right is crucial. Bloom's (1956) taxonomy suggested that through training and education, three types of learning can be achieved: cognitive (developing knowledge), affective (changes in feelings/attitude) and psychomotor (development of manual/physical skills). Evidence suggests that some healthcare providers lack knowledge of how to care for an individual with intellectual disabilities (e.g. Kirschner & Curry 2009). However, it is also known that development of knowledge alone is not sufficient to change behaviour (Morrison *et al.* 1994). As discussed, studies have also demonstrated that some mainstream healthcare professionals demonstrate negative views or attitudes towards individuals with intellectual disabilities, which negatively impacts upon the quality of care they receive (e.g. Lewis & Sternfert-Kroese 2010). Research demonstrates that positive exposure to a marginalized group can positively change the strongest of negative views (Rudman *et al.* 2001). Furthermore, a systematic review conducted by Scior (2011), concluded that prior contact with someone with an intellectual disability, predicts more positive attitudes. Minihan *et al.* (2011) highlight the acquisition of skills in supporting someone with intellectual disabilities through training is sparsely evaluated. However, the three domains (knowledge, attitudes and skills) do not work independently and all are important in improving healthcare services (Minihan *et al.* 2011).

As discussed, there is a drive for individuals with intellectual disabilities to have equal access to mainstream healthcare services. However, there is evidence to suggest that such professionals do not feel confident in meeting the needs of this population, which is likely to be a contributing factor in the poor health outcomes reported. Staff training could therefore be

important in both upskilling professionals as well as improving healthcare outcomes for this client group.

Methodology

The current review utilizes systematic methodology to locate the relevant literature, before employing a narrative approach to examine the perceived needs of professionals and how this might look as a training package. The aims of this review were as follows:

1. To explore the training needs identified by mainstream healthcare staff to support them in working with clients with intellectual disabilities.
2. To critically evaluate the literature base.
3. To synthesize the findings of the review in order to consider the implications for identification of training needs, the facilitation of training and future research.

Studies were included in the review if they presented data following a formal approach to directly assessing the training needs of participants, including qualified professionals working in mainstream adult services (inclusive of those in the later stages of training to become a psychiatrist or a general practitioner, employed within this professional role). No restrictions were placed on date range, age of participants, language or source of publication.

Following a scoping of the literature, a set of terms were derived that were felt to capture those most commonly used within the relevant literature base. The studies were identified utilizing a variety of search strategies including entering key words (three synonyms for intellectual disabilities, two for training, three for staff and three for healthcare systems) within a number of databases (MEDLINE, PsychINFO, CAB Abstracts, Scopus, Web of Knowledge). Frequently cited journals were also hand searched and relevant authors within the field were contacted directly. The search terms yielded 1027 studies and following a screening of the titles, 261 studies remained. The abstracts of these studies were then read and the inclusion and exclusion criteria were applied, leaving 81 papers to be read in full. From this, these papers included for review were identified. A description of these papers can be seen in Table 1.

Analysis

Thematic analysis was conducted across the results of the 13 papers included within this review. This followed the process suggested by Braun and Clarke (2006);

1. Familiarise yourself with the data: This included reading and re-reading the papers several times whilst making general notes.
2. Generating initial codes: This included coding parts of interest throughout each paper. This largely included anything related to boosters and barriers to working with people with intellectual disabilities.
3. Searching for themes: This included collating codes into possible themes.
4. Reviewing themes: Ensuring that all themes were relevant to both the coded data sets and the study data as a whole.
5. Defining and naming themes: This process was also completed by two independent raters, as a means of increasing reliability. General themes identified by all raters were similar, however changes were made to the way in which some of the themes were categorised.

Reviewing the methodology of the studies

A set of criteria by which to judge the external validity of the results in these studies were derived. Threats to external validity were considered important in identifying a core training package. Criteria were employed to the following; study aims, piloting of questionnaires, reporting of statistical power, response rate obtained, appropriateness of data analysis and appropriateness of conclusions made. Studies were scored regarding whether they had sufficiently met, not sufficiently met or if there was not enough information to sufficiently meet the criteria.

The final papers demonstrate that literature specifically measuring the training needs of professionals includes GPs ($n = 4$; with 'Lennox' a common author across three of the studies), palliative care professionals ($n = 4$; with 'Read' and 'Tuffrey-Wijne' authors in two of the studies), psychiatrists ($n = 2$; with 'Lennox' an author in both studies), nurses working in A & E ($n = 1$), primary care practice nurses ($n = 1$) and community pharmacists ($n = 1$). Recruitment strategies included postal questionnaires ($n = 10$), a 'purposive sample' ($n = 1$) and 'convenience samples' ($n = 2$). Sample sizes ranged from 10 to 543. Methodologies amongst the studies also varied, with 62% of the studies ($n = 8$) adopting the use of questionnaires with a quantitative focus during the analysis phase and the remaining 38% ($n = 5$) adopting a more qualitative approach, with analyses reflective of this. This resulted in five studies which used quantitative statistics, two studies used content analysis, two studies

Table 1 Summary of the final 13 papers included in the review

<i>Study</i>	<i>Participants</i>	<i>Measures</i>	<i>Results</i>
Lennox & Chaplin (1996) The psychiatric care of people with intellectual disabilities: the perceptions of consultant psychiatrists in Victoria Australia	227 psychiatrists 48.6% response rate	28-item self-administered questionnaire, designed for this study. 5 sections, including strategies for improving services Likert scale ranging from 'very much agree' to 'very much disagree' regarding the management of people with intellectual disabilities	Further training required regarding: <ul style="list-style-type: none"> • Areas of assessment, diagnosis and treatment of people with dual disabilities. • Improved communication between and understanding of different services and disciplines
Lennox <i>et al.</i> (1997) The general practice care of people with intellectual disability: barriers and solutions Australia	526 GPs 58% response rate	24-item questionnaire, developed for the study. 6-point Likert scale ranging from 'agree strongly' to 'disagree strongly' Included levels of training in intellectual disabilities GPs were also asked to list the three most significant barriers to providing health care to people with intellectual disabilities and ways in which these barriers could be overcome	Further training required regarding: <ul style="list-style-type: none"> • Communication difficulties • History taking with the patient and/or carer • Difficulties in problem determination
Cook & Lennox (2000) General practice registrars' care of people with intellectual disabilities Australia	157 general practice registrars 54.3% response rate	A questionnaire; Section A: 23 statements accompanied by ratings of agreement or disagreement The questionnaire was formulated on that used by Lennox <i>et al.</i> (1997)	Further training required regarding: <ul style="list-style-type: none"> • Communication with someone with intellectual disabilities (i.e. history taking)
Lindop & Read (2000) District nurses' needs: palliative care for people with learning disabilities UK	110 district nurses 64% response rate	Questionnaire developed as a result of two focus groups to identify professional themes. 10 professional needs of district nurses were identified (dependent variables), and five independent variables were identified (qualifications, experience, times of practice, frequency of contact with clients with intellectual disabilities and palliative care needs and type of illness related to palliative care needs). Variables were formulated as questionnaire statements, measured on a 3-point Likert	Further training required regarding: <ul style="list-style-type: none"> • Understanding the nature of an intellectual disability and associated effects • Accurately assessing and managing pain • Being able to interpret communication and alternative communication systems • To be able to assess the level of social competence (undefined in the study)

Table 1 (continued)

<i>Study</i>	<i>Participants</i>	<i>Measures</i>	<i>Results</i>
Phillips <i>et al.</i> (2004) General practitioners' educational needs in intellectual disability health Australia	252 GPs 32.8% response rate for Group A (contact with clients with intellectual disability was known from a database). 27.5% response rate for Group B (contact with clients with intellectual disability was unknown from a database).	scale ranging from greatest to smallest need Questionnaire measured needs in relation to nine health areas, identified following a review of the literature. For each of the nine areas, GPs were asked several questions including the adequacy of their training, whether they would like to receive further training and any other issues related to the health care of people with DD/intellectual disabilities	Further training required regarding: <ul style="list-style-type: none"> • The coordination of care with other services • Forensic issues • Skills for communicating with people with intellectual disabilities • Skills for physical examination of the non-compliant patient
Millar <i>et al.</i> (2004) People with intellectual disability: barriers to the provision of good primary care Australia	43 GPs 14% response rate	Questionnaire previously designed by Cook & Lennox (2000). Additional elements added regarding assessment of secondary barriers; those external to the GP and the result of outside agency. A 6-point Likert scale was used to measure agreement with statements	Further training required regarding: <ul style="list-style-type: none"> • Communication styles, particularly those that could be useful in gaining a patient history
Melville <i>et al.</i> (2005) Enhancing primary health care services for adults with intellectual disabilities UK	201 primary care practice nurses 69% response rate	A purpose designed questionnaire made by the research team: eight subsections with 112 items The questions measured three aspects of efficacy; confidence, satisfaction with skills and perceived difficulty in working with this client group	Further training required regarding: <ul style="list-style-type: none"> • Communicating with people with intellectual disabilities • Contribution of practice nurses • Common health needs of people with intellectual disabilities • What is a learning disability? • Making primary care accessible for people with intellectual disabilities
Tuffrey-Wijne <i>et al.</i> (2005) Supporting patients who have intellectual disabilities: a survey investigating staff training needs UK	46 palliative care professionals. 74% response rate.	A survey originally designed to help plan training sessions for staff was utilized. Main question asked 'what would worry you about working with someone with an intellectual disability?' Questions were open-ended. The questionnaire was piloted beforehand ($n = 16$)	Further training required regarding: <ul style="list-style-type: none"> • Awareness raising of issues specific to this population • Communication and assessment • Pointers to other specialist agencies
Sowney & Barr (2006) Caring for adults with intellectual disabilities: perceived challenges	27 registered A & E nurses 100% participation rate	Five focus groups of five to six participants which lasted for approximately 1 h and were audio-recorded.	Further training required regarding: <ul style="list-style-type: none"> • The nature of intellectual disabilities • Conditions and associated health problems

Table 1 (continued)

Study	Participants	Measures	Results
for nurses in accident and emergency units UK		Data were analysed for themes	<ul style="list-style-type: none"> • Communication • Consent and management issues
Di Blasi <i>et al.</i> (2006) Perspectives on the role of the community pharmacist in the provision of health care to people with intellectual disabilities: exploration of the barriers and solutions Australia	10 community pharmacists 100% participation rate	Semi-structured interview guide developed for this study. Participants were asked to identify barriers to providing care and possible solutions that would overcome the barriers and improve health care. Data were analysed for themes	Further training required regarding: <ul style="list-style-type: none"> • What is an intellectual disability • How to communicate with this client group
Edwards <i>et al.</i> (2007) Queensland psychiatrists' attitudes and perceptions of adults with intellectual disability Australia	175 psychiatrists/psychiatric registrars 43% response rate	28 item self-administered questionnaire (as used by Lennox & Chaplin 1996) featuring multiple choice and open-ended questions. Questions included their responses to 16 statements of opinion regarding the management of adults with intellectual disabilities and details regarding training needs	Further training required regarding: <ul style="list-style-type: none"> • Assessment and diagnosis of mental health difficulties in adults with intellectual disability (clear priority) • Behaviour management and treatment; additional strategies and how to adapt those already used within mainstream populations Evidence base for prescribing to this population <ul style="list-style-type: none"> • General information about intellectual disability and services available • Opportunities to interact with experts In addition to specific health-related issues, such as Syndrome-specific medical problems and behavioural or psychiatric problems
Tuffrey-Wijne <i>et al.</i> (2008) Palliative care provision for people with intellectual disabilities: a questionnaire survey of specialist palliative care professionals UK	543 specialist palliative care professionals 57% response rate.	Questionnaire developed for this study. Participants answered a range of questions about their most recent client with intellectual disabilities, followed by selecting any of 28 potential issues that applied to this client. Participants then ranked the three issues that presented staff with the most problems/topics of training that would be most useful	Further training required regarding: <ul style="list-style-type: none"> • How can I assess pain and symptoms in a patient with an intellectual disability? • How can I understand the way a patient communicates? • How can I involve the patient in decision making? What are the issues around consent to treatment and care? What are the issues for carers and families and how do I support them?

Table 1 (continued)

<i>Study</i>	<i>Participants</i>	<i>Measures</i>	<i>Results</i>
Cartlidge & Read (2010) Exploring the needs of hospice staff supporting people with an intellectual disability: a UK perspective UK	43 palliative care staff Over 50% response rate for questionnaire and $n = 17$ for the focus group	Two questionnaires and a focus group discussion were utilized. Focus group data were analysed for themes. The questionnaire collected demographic data as well as information regarding the challenges of working with someone with intellectual disabilities/what may help make these challenges easier	Further training required regarding: <ul style="list-style-type: none"> • People with an intellectual disability (what it means to have an intellectual disability) • Knowledge, including constructive opportunities for personal and professional reflection on past experiences of care provided • Management of conditions • Communication • Values/attitudes

used thematic analysis and one study used an unspecified qualitative analysis. Those that used content analysis described sorting questionnaire items into key themes or concepts and then completing a frequency count of the items in each category (e.g. Tuffrey-Wijne *et al.* 2005). Thematic analysis was described by Di Blasi *et al.* (2006) as coding full interview transcriptions for emerging themes, with coding occurring in three stages; open, axial and selective coding.

There are varying areas of strength and weakness across the studies. A particular area of strength across the studies (77%) was the degree to which conclusions made were linked to the results reported. Furthermore, where thoroughly reported, analyses (62%) proved strong. Many studies conducted several methods of analysis, as well as ensuring reliability of results by employing the help of further independent raters within the qualitative elements.

Areas of potential weakness within this field are consideration of power or adequacy of sample sizes recruited, as well as response rates achieved. Eight out of the 13 studies (with two not reporting enough information), did not achieve the recommended response rate of 60%, making generalisability of their results challenging. It is important to note here that there were varying methods of recruitment utilised across the studies (purposive samples, convenience samples and postal questionnaires) which may have impacted not only on the likelihood of consent from participants, but also on their data provided. Further to this, seven of the quantitative studies made no reference to *post-hoc* power, or to the adequacy of their sample size in allowing for appropriate analysis of data.

Lindop & Read (2000); Melville *et al.* (2005) and Tuffrey-Wijne *et al.* (2005) were identified as the strongest

papers. It is important to note that these studies were not the strongest by a large margin, but received fewer ratings indicating threats to validity than the other studies. Nonetheless, given their strengths across all other areas, the greatest amount of confidence can be had in the results obtained within these three studies.

Melville *et al.* (2004) received the most ratings indicating threats to external validity. This was due to the lack of information presented within the paper, therefore making it difficult to ascertain the aims of the study, whether a pilot phase had taken place, what analyses had been used and whether the conclusions were a true reflection of the results. With an achieved response rate of only 14%, the results of this study must be interpreted with caution. However, it must be acknowledged that this study is written up as a short report and therefore it may have been at a disadvantage when applied to the evaluation table.

Although some papers have been identified as stronger than others, the differences between the quality of the papers was small. Due to this and the relative novelty of this field, it was deemed important to take into account all of the final thirteen papers within this review.

Measures

Given that the current research within this topic area remains exploratory, it is important to highlight the varying means with which authors are assessing the needs of professionals and the impact this could have on results. Eleven studies (Lennox & Chaplin 1996; Lennox *et al.* 1997; Cook & Lennox 2000; Lindop & Read 2000; Millar *et al.* 2004; Phillips *et al.* 2004; Melville *et al.* 2005; Tuffrey-Wijne *et al.* 2005; Edwards *et al.* 2007; Tuffrey-Wijne *et al.* 2008; Cartlidge & Read 2010) used

questionnaires that were designed for the purpose of their current study. The style of questionnaires varied across studies however. Several studies (Lennox & Chaplin 1996; Lennox *et al.* 1997; Cook & Lennox 2000; Millar *et al.* 2004; Phillips *et al.* 2004; Melville *et al.* 2005; Edwards *et al.* 2007) adopted a format of producing statements regarding the care of individuals with intellectual disabilities which participants rated on varying Likert scales, indicating levels of agreement or disagreement. Following this, some researchers (Lennox & Chaplin 1996; Lennox *et al.* 1997; Phillips *et al.* 2004; Edwards *et al.* 2007) used an open ended question related to barriers and solutions regarding access to healthcare or any other pertinent issues. Within these studies, this question appeared to be the means by which training needs were assessed.

Two studies utilised different methods; Di Blasi *et al.* (2006) who conducted a semi-structured interview and Sowney & Barr (2006) who conducted focus groups. The possible impact of the implementation of all methods on the results gained will be explored in the discussion section of this review.

Themes

Following a process of thematic analysis (Braun & Clarke 2006) three main themes were identified across the studies: general communication, knowledge/information, profession specific needs.

Theme 1: General communication

Nine of the thirteen papers identified training regarding general communication with individuals with intellectual disabilities to be a priority (Lennox *et al.* 1997; Lindop & Read 2000; Phillips *et al.* 2004; Melville *et al.* 2005; Tuffrey-Wijne *et al.* 2005, 2008; Di Blasi *et al.* 2006; Sowney & Barr 2006; Cartlidge & Read 2010). This was a common training need identified across GPs, palliative care professionals, community pharmacists, primary care practice nurses and nurses working in Accident and Emergency (A&E). This is significant given that research indicates difficulties in communicating with healthcare staff are also a concern for individuals with intellectual disabilities (Gibbs *et al.* 2008).

A large sample of palliative care professionals ($n = 110$; Lindop & Read 2000) reported they would like training to both interpret communication from clients with intellectual disabilities and be taught alternative communication systems. These participants were, however asked to rate a list of training suggestions as

proposed by a smaller group of palliative care professionals ($n = 12$). The results may therefore not be a true reflection of the training needs of that staff group *per se*, but the highest priority from the list available.

Interestingly, neither of the studies that asked about the training needs of psychiatrists (Lennox & Chaplin 1996; Edwards *et al.* 2007) identified general communication as a need. Furthermore, neither identified profession-specific communication needs. Instead, this participant group's needs were focused around the assessment, diagnosis and treatment of psychiatric or mental health disorders, as well as information regarding specialist services. This difference between psychiatrists and other professional groups may be due to all of the psychiatrists asked, having had some regular contact with clients with intellectual disabilities. More frequent contact with this client group, compared to the other professionals asked, may have been sufficient in providing enough confidence regarding communicating with such clients. Cook & Lennox (2000) and Millar *et al.* (2004) also reported no general communication training needs for the GPs asked; however, both groups reported specific communication needs, as will be discussed.

Theme 2: Knowledge/Information

Of intellectual disability generally

An emerging theme across the studies was the need for training to provide participants with greater knowledge regarding intellectual disabilities (Lindop & Read 2000; Melville *et al.* 2005; Tuffrey-Wijne *et al.* 2005; Di Blasi *et al.* 2006; Sowney & Barr 2006; Cartlidge & Read 2010). This need largely focused around understanding more about the definition of intellectual disability (Lindop & Read 2000; Melville *et al.* 2005; Di Blasi *et al.* 2006; Sowney & Barr 2006).

It may be a reflection of the nature of medical training that no studies focusing upon GPs or psychiatrists (Lennox & Chaplin 1996; Lennox *et al.* 1997; Cook & Lennox 2000; Millar *et al.* 2004; Edwards *et al.* 2007) identified knowledge regarding intellectual disabilities in general as a training need. The definition of intellectual disability is diagnostic and therefore is likely to be included within medical training, therefore possibly eliminating the need for this to be revisited.

Local specialist services/consultation

Amongst some samples of GPs (Phillips *et al.* 2004), psychiatrists (Lennox & Chaplin 1996; Edwards *et al.*

2007) and palliative care professionals (Tuffrey-Wijne *et al.* 2005; Cartlidge & Read 2010), knowledge and information regarding local specialist intellectual disability services was highlighted as a training need. Specifically, opportunities to liaise and interact with specialist professionals were reported to be a popular suggestion for inclusion within training by GPs and psychiatrists (Lennox & Chaplin 1996; Phillips *et al.* 2004; Edwards *et al.* 2007).

Theme 3: Profession-specific needs

Across the final thirteen papers, a number of the themes identified are considered 'profession specific'. This indicates that whilst there are some similarities between professional groups, specific areas of training may have a different focus, depending upon the professionals attending.

Assessment

One of the largest themes identified across the papers was assessment of clients and their needs (Lennox & Chaplin 1996; Lennox *et al.* 1997; Lindop & Read 2000; Tuffrey-Wijne *et al.* 2005, 2008; Edwards *et al.* 2007). This was identified by palliative care professionals, GPs and psychiatrists and covered issues such as identifying the presenting problem or difficulty, as well as assessing individual's symptoms or pain. One group of palliative care professionals (Lindop & Read 2000) also identified being able to assess an individual's level of social competence as an important training need. However once again, this was rated from a pre-existing list of possible training needs and therefore should be tentatively interpreted.

A theme emerged from GPs regarding training in the process of history taking with a client (Lennox *et al.* 1997; Cook & Lennox 2000; Millar *et al.* 2004). It is of interest that Cook & Lennox (2000) completed their survey with a sample of GP registrars, who were both in employment as practising GPs and partaking in education prior to gaining full qualification. Despite this ongoing training, registrars indicated the same training needs as qualified GPs, both 3 years earlier and 4 years later. This indicates a reasonably stable time frame over which this training need has been identified and could suggest that it is not well covered within medical training. However, there is only one study within this review that includes registrars, and therefore, this hypothesis is tentative.

Phillips *et al.* (2004) reported that GPs would also find it beneficial to be taught 'skills for the physical

examination of the non-compliant patient'. This was an issue identified as a priority amongst a sample of 363 GPs, and therefore whilst still interpretable with caution, it is nonetheless of note.

It is interesting to note that the samples of community pharmacists (Di Blasi *et al.*, 2006), nurses in A&E (Sowney & Barr 2006) and primary care nurses (Melville *et al.* 2005) did not identify assessment-related training needs, given that clinical assessment is a dominant part of their job role (e.g. Endacott *et al.* 1999; The Primary and Community Care Pharmacy Network (PCCP) 2009). However, there is only one study regarding each of these professions within this review, and therefore, this cannot be considered a generalizable finding amongst these professional groups.

Diagnosis

GPs (Lennox *et al.* 1997) and psychiatrists (Lennox & Chaplin 1996; Edwards *et al.* 2007) identified training regarding diagnosis and recognition of disorders among clients with intellectual disabilities as priorities. As to be expected, GPs focused upon diagnosis of physical health conditions and psychiatrists upon diagnosis of psychiatric disorders. This finding suggests that in using the same questionnaire and sampling the same professional group, this diagnosis-related training need appeared to remain stable over a decade (Lennox & Chaplin 1996; Edwards *et al.* 2007).

Linked to diagnosis was the need for training regarding health complications and difficulties that might be more prevalent in clients with intellectual disabilities (Phillips *et al.* 2004; Melville *et al.* 2005; Sowney & Barr 2006; Edwards *et al.* 2007). This was highlighted across GPs, primary healthcare nurses, palliative care professionals, nurses in A&E and psychiatrists. Within primary care settings (Phillips *et al.* 2004; Melville *et al.* 2005), participants reported that a greater understanding of specific health conditions more common in individuals with intellectual disabilities would enable them to provide a better service to this client group. However, the low response rate as obtained by Phillips *et al.* (2004) suggests that their results should be interpreted with caution.

Psychiatrists (Edwards *et al.* 2007) indicated a greater interest in syndrome-specific medical problems. This was similar to the need identified by nurses working in A&E (Sowney & Barr 2006), who felt that lacking such knowledge left them feeling fearful of encountering such a client group at work. It is important to note, however, that this participant sample was small

($n = 27$), and therefore, such results must be interpreted with caution.

Intervention and management

This subtheme relates to training needs identified regarding the requirement of knowledge about an aspect of supporting clients with intellectual disabilities within specific professional areas.

A sample of palliative care professionals (Tuffrey-Wijne *et al.* 2008) and nurses working in A&E (Sowney & Barr 2006) shared a common prioritized training need regarding gaining client consent. Neither professional group had a clear understanding of how to ensure that fully informed consent was obtained, whether it was necessary and what (if any) alternative steps could be taken if gaining consent was not possible.

Psychiatrists required greater knowledge and training in the types of medication used with individuals with intellectual disabilities (Lennox & Chaplin 1996) as well as a need for training regarding behaviour treatment and the evidence base for prescribing medication with such a client group (Edwards *et al.* 2007). GPs (Phillips *et al.* 2004) ranked the order in which they prioritized requiring greater knowledge on a set of healthcare issues. The top three, as ranked by a large sample, ($n = 363$) were preventative and primary health care, syndrome-specific medical problems and behavioural or psychiatric problems.

Edwards *et al.* (2007) found that psychiatrists considered learning how to adapt management strategies for use with individuals with intellectual disabilities, a priority for training. This was identified amongst a large sample ($n = 175$); however, it is interesting to note that Lennox & Chaplin (1996) did not find that this was a priority amongst their psychiatry participants. Both studies utilized the same self-administered questionnaire, amongst an Australian population. However, the 11 year difference in timescale between the studies may reflect the difference in needs of psychiatrists over a decade (Torr *et al.* 2008).

Palliative care professionals (Lindop & Read 2000; Cartlidge & Read 2010), psychiatrists (Lennox & Chaplin 1996; Edwards *et al.* 2007) and A&E nurses (Sowney & Barr 2006) all identified varying management skills that were required in order for them to feel competent in caring for someone with intellectual disabilities. Palliative care professionals identified a need for training in the management of conditions generally within this population, specific behavioural problems (Cartlidge & Read 2010) and the management of pain (Lindop & Read

2000). Once again, generalizability of these results is limited, due to the small sample size ($n = 43$; Cartlidge & Read 2010) and pre-existing list provided to participants within the study (Lindop & Read 2000).

Tuffrey-Wijne *et al.* (2008) and Cartlidge & Read (2010) identified that palliative care staff desired training in understanding the issues relevant to carers and families and managing complex family dynamics. This difference when compared to the needs of the other professionals could be due to the differing nature of the service provided within a palliative care setting (National Institute of Clinical Excellence; NICE, 2004).

Discussion

From the available literature examining the training needs of mainstream healthcare professionals to support or prepare them for working with clients with intellectual disabilities, three main themes were identified: general communication, knowledge/information and profession specific. Generally, there was a great deal of overlap in needs identified by professional groups, indicating that a core training package is feasible. The 'profession-specific' subthemes may require greater depth and specificity around the job role of different professional groups, as an 'add-on' to the main package. However, some consideration must be given to the relative scarcity of research regarding this topic and the small number of studies located per professional group, when making conclusions as to the contents of a comprehensive training package. When considering the literature in relation to Bloom's (1956) taxonomy, it is interesting to note that the needs identified could be considered applicable to acquiring both knowledge and skills, but not changes in attitude or values.

Literature suggests that attitudes of healthcare professionals are one of the biggest barriers to individuals with intellectual disabilities receiving equitable access to services (Lewis & Sternfert-Kroese 2010), and in order for change to be effective, development in all three domains is necessary (Minihan *et al.* 2011). However, only Cartlidge & Read (2010) highlighted attitudes and values training with regards to supporting palliative care professionals to care for someone with an intellectual disability as important. Whilst the authors did not explore the definition or meaning of this in great depth, they discussed the need to ensure that healthcare professionals receive training opportunities that help with 'demystifying any associated anxieties, fears and apprehensions' (p. 98) regarding working with such a client group. The authors

recognise that otherwise 'many services harbour misguided negative assumptions regarding marginalized groups, and such stigma can serve as a barrier to effective care and support' (p. 98).

It is therefore important to consider and explore further the reasons why this is not identified as a training need by many professional groups. We know that when specifically asked about attitudes in an anonymous questionnaire, staff do report less favourable attitudes and beliefs (e.g. McConkey & Truesdale 2000). However, it is possible that when not made explicit, professionals feel reluctant to raise this as a need or fail to recognize it at all. As a starting point, it is possible that by utilizing different methodologies when assessing attitudes (for example asking managers to rate the values and attitudes of their team overall or colleagues to rate each other), a more accurate representation could be gained. Nonetheless, this gap should also be acknowledged when considering the development of a core training package for mainstream healthcare staff, as based on the needs identified within this review, attitudes could otherwise be forgotten.

Although not included within the review itself, since it did not ask staff specifically for their training needs, Tuffrey-Wijne *et al.* (2013) completed an important study which summarises some findings of similar themes to that presented within this review. When looking at the barriers to safety of individuals with intellectual disabilities in hospitals, they concluded that such a client group's safety was compromised due to the invisibility of clients with an intellectual disability (i.e. attitudes of professionals) as well as a lack of understanding among the staff as to what it means to have an intellectual disability. This study is important in providing further evidence of the necessity of these training needs as well as highlighting that these themes remain an ongoing need.

As previously highlighted, many of the studies within this review utilized new measures and few reported on their psychometric properties, which could have an impact upon the quality of the results. Although firm conclusions are not possible with such few studies and no formal statistics, there appears to be evidence for the reliability of two of the questionnaires (e.g. Cook & Lennox 2000; Edwards *et al.* 2007), given the similarities in the content of the results described. Whilst quantitative questionnaires allow for rigorous statistical analysis, Tuffrey-Wijne *et al.* (2005) and Cartlidge & Read (2010) demonstrated the richness that could be gained from utilizing open-ended questions. This allowed the authors to extract a variety of themes and have some confidence

that what was generated was that which was considered pertinent to the individuals asked.

Most different to the other methods used were the semi-structured interview (Di Blasi *et al.*, 2006) and focus groups (Sowney & Barr 2006), both gaining a large amount of rich data which could contribute a lot to the research field. However, a less structured approach also raises its own difficulties in determining the validity and reliability of the results obtained.

As this review demonstrates, mainstream healthcare staff show insight into their training needs, required to help them to feel better skilled and confident in working with clients with intellectual disabilities. The way in which such needs are met requires further consideration and creativity to ensure its suitability for a particular setting. It is possible that some of the 'knowledge'-based needs could be provided within a handbook or through generic 'multiprofession' training sessions. Although there is not yet evidence to support this, it is possible that attitudes training could be delivered in the same way across common settings such as NHS Trusts. It is likely that more time would be needed for training sessions aimed at developing profession-specific skills. Such training sessions may be more effective if delivered in part by specialist intellectual disability practitioners (to allow the opportunity for professionals to liaise/consult), as well as individuals with intellectual disabilities (to increase the ability for attendees to contextualize their learning).

Two possible limitations of this research field were identified through this review: the measures used and sample considerations. As discussed, the validity and reliability of the questionnaires used remain unclear and often make having full confidence in the results obtained difficult. Almost all of the studies devised new questionnaires, and steps taken to ensure validity, reliability or acceptability varied considerably. An avenue for future research includes the development of a standardized measure that can be used across professional settings to more confidently capture the needs of healthcare professionals.

A further limitation within many of the studies was the participant samples. Often, sample sizes were small (Millar *et al.* 2004; Di Blasi *et al.*, 2006; Tuffrey-Wijne *et al.* 2005; Sowney & Barr 2006; Cartlidge & Read 2010) and they varied as to how much contact (if any) professionals had with individuals with intellectual disabilities. More often than not, the impact of this difference in experience was not analysed, and where it was (Lindop & Read 2000; Phillips *et al.* 2004), no significant differences were found in training need

depending on experience gained. It is therefore unclear how much of a limitation varied experience across the participant group is.

Limitations of the review itself are also acknowledged. Due to the relative scarcity of the research specifically looking at this topic area, all studies were included regardless of methodology, participant type or method of analysis. Whilst this could also be considered a strength, its limitation is important to note in that applying a systematic evaluation grid to all papers proved challenging.

However, this review has highlighted the developing body of literature that seeks to identify the needs of mainstream staff when working with clients with intellectual disabilities. It indicates that developing a core training package that can be implemented across different professional settings is possible and that this could have an important role in increasing the equality in access to and quality of health care for people with intellectual disabilities. It is suggested that further research specifically with GPs is important, since they are often the healthcare professionals who will see clients from a young age, through into adulthood. Ensuring that this professional group feel sufficiently trained to support individuals with intellectual disabilities could therefore contribute to this client group receiving high quality healthcare from a young age. This could ultimately see such a client group in better physical and mental health into adulthood also. Furthermore, within this review no studies were found that assessed the training needs of psychological therapists who are now required to provide talking therapies for individuals with intellectual disabilities (DOH 2009). This is also highlighted as an important professional group with which to conduct this research. Finally, studies that evaluate the delivery of the training for mainstream healthcare professionals itself is much needed.

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References

- Bloom B. S. (1956) *Taxonomy of Educational Objectives, Handbook I: The Cognitive Domain*. David McKay Co Inc, New York, NY.
- Bowling A. (1997) *Research Methods in Health: Investigating Health and Health Services*. Open University Press, Buckingham.
- Braun V. & Clarke V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 77–101.
- Cartlidge D. & Read S. (2010) Exploring the needs of hospice staff supporting people with an intellectual disability: a UK perspective. *International Journal of Palliative Nursing* 16, 93–98.
- Cook A. & Lennox N. (2000) General practice registrars' care of people with intellectual disabilities. *Journal of Intellectual and Developmental Disability* 25, 69–77.
- Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. The Stationary Office, London.
- Department of Health (2009) *Valuing People Now: A New Three-Year Strategy for Learning Disabilities*. The Stationary Office, London.
- Department of Health (2011) *No Health without Mental Health*. The Stationary Office, London.
- Di Blasi A., Kendall S. & Spark M. (2006) Perspectives on the role of the community pharmacist in the provision of healthcare to people with intellectual disabilities: exploration of the barriers and solutions. *The International Journal of Pharmacy Practice* 14, 263–269.
- Edwards N., Lennox N. & White P. (2007) Queensland psychiatrists' attitudes and perceptions of adults with intellectual disability. *Journal of Intellectual Disability Research* 50, 75–81.
- Emerson E. & Baines S. (2010) *Health Inequalities and People with Learning Disabilities in the UK: 2010. Improving Health and Lives: Learning Disabilities Observatory*. Available at: <http://www.improvinghealthandlives.org.uk/publications> (accessed on 10 March 2013).
- Emerson E. & Hatton C. (2007) Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry* 191, 493–499.
- Emerson E., Madden R., Robertson J., Graham H., Hatton C. & Llewellyn G. (2009) *Intellectual and Physical Disability, Social Mobility, Social Inclusion and Health: Background Paper for the Marmot Review*. Centre for Disability Research, Lancaster University, Lancaster.
- Endacott R., Edwards B., Crouch R., Castille K., Dolan B., Hamilton C., Jones G., MacPhee D. & Manley K. (1999) Clinical competency-framework, emergency nursing. *Emergency Nurse* 7, 10–16.
- Equality Act (2010) The Stationary Office, London. Available at: <http://www.legislation.gov.uk/ukpga/2010/15> (accessed on 20 March 2013).
- Gibbs S. M., Brown M. J. & Muir W. J. (2008) The experiences of adults with intellectual disabilities and their carers in general hospitals: a focus group study. *Journal of Intellectual Disability Research* 52, 1061–1077.
- Glover G., Emerson E. & Evison F. (2012) *The Uptake of Health Checks for Adults with Learning Disabilities: 2008/9 to 2011/12. Improving Health and Lives: Learning Disabilities Observatory*, Department of Health.

- Kirschner K. L. & Curry R. H. (2009) Educating health care professionals to care for patients with disabilities. *Journal of the American Medical Association* **302**, 1334–1335.
- Lennox N. & Chaplin R. (1996) The psychiatric care of people with intellectual disabilities: the perceptions of consultant psychiatrists in Victoria. *The Australian and New Zealand Journal of Psychiatry* **30**, 774–780.
- Lennox N., Diggins J. & Ugoni A. (1997) The general practice care of people with intellectual disability: barriers and solutions. *Journal of Intellectual Disability Research* **41**, 380–390.
- Lewis S. & Sternfert-Kroese B. (2010) An investigation of nursing staff attitudes and emotional reactions towards patients with intellectual disability in a general hospital setting. *Journal of Applied Research in Intellectual Disabilities* **23**, 355–365.
- Lindop E. & Read S. (2000) District nurses' needs: palliative care for people with learning disabilities. *International Journal of Palliative Nursing* **6**, 117–122.
- McConkey R. & Truesdale M. (2000) Reactions of nurses and therapists in mainstream health services to contact with people who have intellectual disabilities. *Journal of Advanced Nursing* **32**, 158–163.
- Melville C., Finlayson J., Cooper S.-A., Allan L., Robinson N., Burns E., Martin G. & Morrison J. (2005) Enhancing primary health care services for adults with intellectual disabilities. *Journal of Intellectual Disability Research* **49**, 190–198.
- Mencap (2007) *Death by Indifference*. Mencap, London.
- Millar L., Chorlton M. & Lennox N. (2004) People with intellectual disability: barriers to the provision of good primary care. *Australian Family Physician* **33**, 657–658.
- Minihan P., Robey K., Long-Bellil L., Graham C., Hahn J., Woodard L. & Edey G. (2011) Desired educational outcomes of disability-related training for the generalist physician: knowledge, attitudes and skills. *Academic Medicine* **86**, 1171–1178.
- Monitor (2013) *Monitor Compliance Framework 2013/14. Monitor Publication Code IRG 07/13*. Available at: <http://www.monitor-nhsft.gov.uk/sites/default/files/publications/ToPublishComplianceFramework201314March13.pdf> (accessed on 01 June 2013).
- Morrison D. M., Baker S. A. & Gillmore M. R. (1994) Sexual risk behaviour, knowledge, and condom use among adolescents in juvenile detention. *Journal of Youth and Adolescence* **23**, 271–288.
- Moser C. A. & Kalton G. (1971) *Survey Methods in Social Investigation*. Heinemann, London.
- National Health Service (2009) *Improving Access to Psychological Therapies. Learning Disabilities Positive Practice Guide*.
- National Institute of Clinical Excellence (2004) *Improving Supportive and Palliative Care for Adults with Cancer*. Available at: <http://www.nice.org.uk/csgsped> (accessed on 14 January 2013).
- Phillips A., Morrison J. & Davis R. (2004) General practitioners' educational needs in intellectual disability health. *Journal of Intellectual Disability Research* **48**, 142–149.
- Primary and Community Care Pharmacy Network (2009) *A Competency Framework for Community Health Pharmacy Services*. 2nd edn. Available at: http://www.pccpnetwork.nhs.uk/documents/PCCPN_competency_framework_2nd_dition_April_2009authors_links.pdf (accessed on 03 February 2013).
- Rudman L. A., Ashmore R. D. & Gary M. L. (2001) "Unlearning" automatic biases: the malleability of implicit prejudice and stereotypes. *Journal of Personality and Social Psychology* **81**, 856–868.
- Scior K. (2011) Public awareness, attitudes and beliefs regarding intellectual disability: a systematic review. *Research in Developmental Disabilities* **32**, 2164–2182.
- Sowney M. & Barr O. (2006) Caring for adults with intellectual disabilities: perceived challenges for nurses in accident and emergency units. *Journal of Advanced Nursing* **55**, 36–45.
- Sweeney J. (2004) Beyond the rhetoric; access to Mainstream Health Service in Ireland. *Learning Disability Practice* **7**, 28–33.
- Torr J., Lennox N., Cooper S.-A., Rey-Conde T., Ware R. S., Galea J. & Taylor M. (2008) Psychiatric care of adults with intellectual disabilities: changing perspectives over a decade. *Australian and New Zealand Journal of Psychiatry* **42**, 890–897.
- Tuffrey-Wijne I., Hollins S. & Curfs L. (2005) Supporting patients who have intellectual disabilities: a survey investigating staff training needs. *International Journal of Palliative Nursing* **11**, 182–188.
- Tuffrey-Wijne I., Whelton R., Curfs L. & Hollins S. (2008) Palliative care provision for people with intellectual disabilities: a questionnaire survey of specialist palliative care professionals. *Palliative Medicine* **22**, 281–290.
- Tuffrey-Wijne I., Giatras N., Goulding L., Abraham E., Fenwick L., Edwards C. & Hollins S. (2013) Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: a mixed methods study. *Health Services and Delivery Research* **1**, 1–225.