

An integrative review of the hospital experiences of people with an intellectual disability: Lack of orthopaedic and trauma perspectives.

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INTRODUCTION

The United Nations Convention on the Rights of Persons with Disabilities (2006) states the rights of disabled people to *'enjoyment of the highest standards of health without discrimination on the basis of disability'* (article 25). Despite this, the level of care provided for people with intellectual disabilities (PWID) in general hospitals has been an area of concern due to evidence of abuse, neglect and discrimination (Disability Rights Commission, 2006) as well as evidence of premature deaths in hospitals (Heslop *et al.*, 2013). Following the harrowing report, 'Death by Indifference' (Mencap, 2007) in which it was highlighted that PWID died as a result of poor hospital care in the UK, there have been numerous reports, policy guidance and legal requirements issued to provide direction for hospital services, for example: Michael (2008); Emerson *et al.* (2012a; 2012b).

Background

The International Classification of Diseases (2010) (ICD-10) describes intellectual disability as,

...a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities.

Musculoskeletal conditions are typically characterised by pain which may be persistent as well as limitations in mobility, dexterity and functional ability (World Health Organisation, (WHO) 2018). However, dealing with pain can be a challenging task for PWID who may face barriers to having pain addressed if they cannot provide valid self-reports or are unable to explain their symptoms (Skorpen, Nicolaisen and Langballe, 2016). Burke *et al.* (2016) agree that as communication may be difficult

for PWID, osteoporotic fractures may go undiagnosed if PWID are not assessed or if they are misunderstood. It is reported by the International Osteoporosis Foundation (2020) that there is an under-reporting of vertebral fractures in people without intellectual disabilities and this constitutes a missed opportunity to prevent subsequent fractures, including life-threatening hip fractures. Furthermore, PWID have additional risks for osteoporosis, such as use of anti-epileptic drugs, early menopause, poor dietary intake of calcium, they may be immobilised for long periods with low levels of physical activity, there may be insufficient exposure to sunlight to maintain adequate vitamin D level, they are not undergoing risk assessment for fractures or having the gold standard, DEXA scan, to diagnose osteoporosis or receiving preventative measures (National Osteoporotic Society, 2015). A study undertaken in Norway by Skorpen, Nicolaisen and Langballe (2016) concurred with the study undertaken by Burke *et al.* (2016), that osteoporosis is under-diagnosed in PWID. Notwithstanding the difficulties that a person can have in communicating their pain if they have a fracture, the carers may not know or understand that the person is in pain. Büchele *et al.* (2017) found that there was a high fracture rate in PWID and the comparable risks of femoral fracture occurred about 10–15 years earlier in females and even 20–40 years earlier in males with intellectual disabilities than in the general population.

A large, population-based cross-sectional study undertaken in Scotland, UK concluded that the most prevalent physical health conditions affecting PWID included: osteoporosis, bone deformity and musculoskeletal pain (Kinnear *et al.*, 2018). A significant proportion (48%) of PWID were found to have musculoskeletal conditions. Although this study was undertaken in one region of Scotland it

highlights the high prevalence of these conditions amongst PWID. Burke *et al.* (2019) concur that the prevalence of poor bone health in PWID is substantial implying an increased risk of fracture due to reduced skeletal integrity.

Finlayson (2011) and Finlayson *et al.* (2010; 2014) reported that PWID sustain more injuries, falls and accidents than the general population. Eye disease is associated with falls risk and is highly prevalent among older PWID (McCarron *et al.*, 2013). Fractures may occur from a low impact injury if a person has osteoporosis and this places PWID at an increased risk of injury following a fall (Cox *et al.*, 2010).

Hospital care

Phillips (2019) highlighted that being in hospital can be difficult for anybody, but it is particularly challenging for PWID and compared with the general population, PWID are more likely to need and use health services: they have poorer experiences of care and worse health outcomes. Mainstream health services have had difficulty in providing an equitable service for PWID compared with the general population (Mencap, 2007; Emerson and Baines, 2011; Heslop *et al.*, 2013). Bradbury-Jones *et al.* (2013) and Iacono *et al.* (2014) undertook systematic reviews related to hospital care for PWID and concur that the health, safety and welfare of PWID in general hospitals was not only poor but unsafe too; there was a failure of hospital staff to meet the needs of PWID. Iacono *et al.* (2014) highlighted the need for further research to identify and investigate hospital care at specific points of encounter across a hospital journey.

As far back as 2004, The National Patient Safety Agency (NPSA) identified the vulnerability of PWID in general hospitals and found that they were at an increased risk of harm whilst in this environment. Particular areas of concern and potential risk factors were: communication difficulties; lack of intellectual disability training for health staff; additional health concerns such as epilepsy not being recognised by the hospitals; the assumption by general hospital staff that intellectual disability staff and carers can provide full nursing care; and issues around consent (NPSA, 2004). The Learning Disabilities Mortality Review (LeDeR Programme) (National Health Service England, 2018) reports on the deaths of PWID and has demonstrated that many PWID died in hospital care and on average up to twenty years younger than people without an intellectual disability.

Theoretical Framework

Person-centredness is a term that has become internationally recognised within health and social care. McCormack and McCance (2010, p. 13) describe person-centredness as:

An approach to practice established through the formation and fostering of therapeutic relationships between all care providers, people and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development.

Person-centred care was the theoretical framework used to guide this review (Ravitch and Riggan, 2017). The benefits of person-centred care have been recognised by the WHO (2015) and the recent proficiencies for future registered nurses in the UK (Nursing and Midwifery Council (NMC), 2018, p. 38).

THE REVIEW

Aim

The original aim of the review was to provide an overview and appraisal of the research studies about the orthopaedic and trauma hospital experiences of PWID. However, there were no published empirical studies relating to orthopaedic or trauma hospital care from the perspectives of PWID so the aim was revisited and amended to provide an overview and appraisal of the research studies about the general hospital experiences of PWID. Alongside this, the aim was to highlight the gaps in the evidence-based literature in this area. The review question was: What are the hospital experiences of adults with an intellectual disability?

Design

According to Whittemore and Knafl (2005), an integrative review (IR) has the potential to play a greater role in evidence-based practice due to its breadth along with the inclusion of literature using diverse primary research methods. The IR was guided by the method described by Whittemore and Knafl (2005) and included identifying the problem, searching the literature, data evaluation, analysis and then interpretation and presentation of results.

Search methods

The following electronic databases were searched: Academic Search Complete, Nursing and Allied Health, British Nursing Index (BNI) and Royal College of Nursing (RCN) Library Archive, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (MEDLINE), Psychological Information Database (PsychINFO), The Cochrane Collaboration

Database and Google Scholar. After this, the reference lists from the papers that were included in the final review were scrutinised to identify further relevant papers.

The literature search included a review of information from books, journal articles, policy documents and national guidelines which were used for background information. The final sample of literature comprised of primary research literature about hospital experiences of PWID as this was consistent with the inclusion criteria and the overall purpose of this review.

The inclusion criteria were: (i) empirical qualitative, quantitative or mixed-methods studies; (ii) published between January 2007 – May 2020; (ii) in the English language; (iii) which included the perspectives of PWID on their hospital experiences; (iv) who were adults 18 years old and over with an intellectual disability; and (v) the paper contained exploration or evaluation of the general hospital experience. The exclusion criteria were: studies that did not include adults with an intellectual disability as participants or studies that were unrelated to general hospital care.

A literature search was undertaken in 2014, 2015, 2018 and again in May 2020 because the literature review was part of a 6 year part-time doctoral research study which commenced in 2014. The time period was January 2007- May 2020 which spans thirteen years. The rationale for this time period was that a highly influential and public landmark report entitled, 'Death by Indifference' (Mencap, 2007) was published and received sustained media attention in the public domain due to the shocking and preventable deaths of six young PWID in hospital care. This was a watershed report where the lack of equity and quality of care for PWID was raised in

the public domain. Each search was limited to title and abstracts that were available in the English language, adults with an intellectual disability as participants in the empirical study and evidence that a peer review process had been undertaken.

The search terms that were used are listed in Table 1. The asterisk indicates that all terms beginning with this root were searched. The Boolean operators 'or' and 'and' were utilised to obtain the available studies. Given the historical changes and geographical differences in terminology utilised to describe PWID numerous search terms were employed to ensure maximum coverage.

Table 1 The search terms that were used in each of the electronic databases

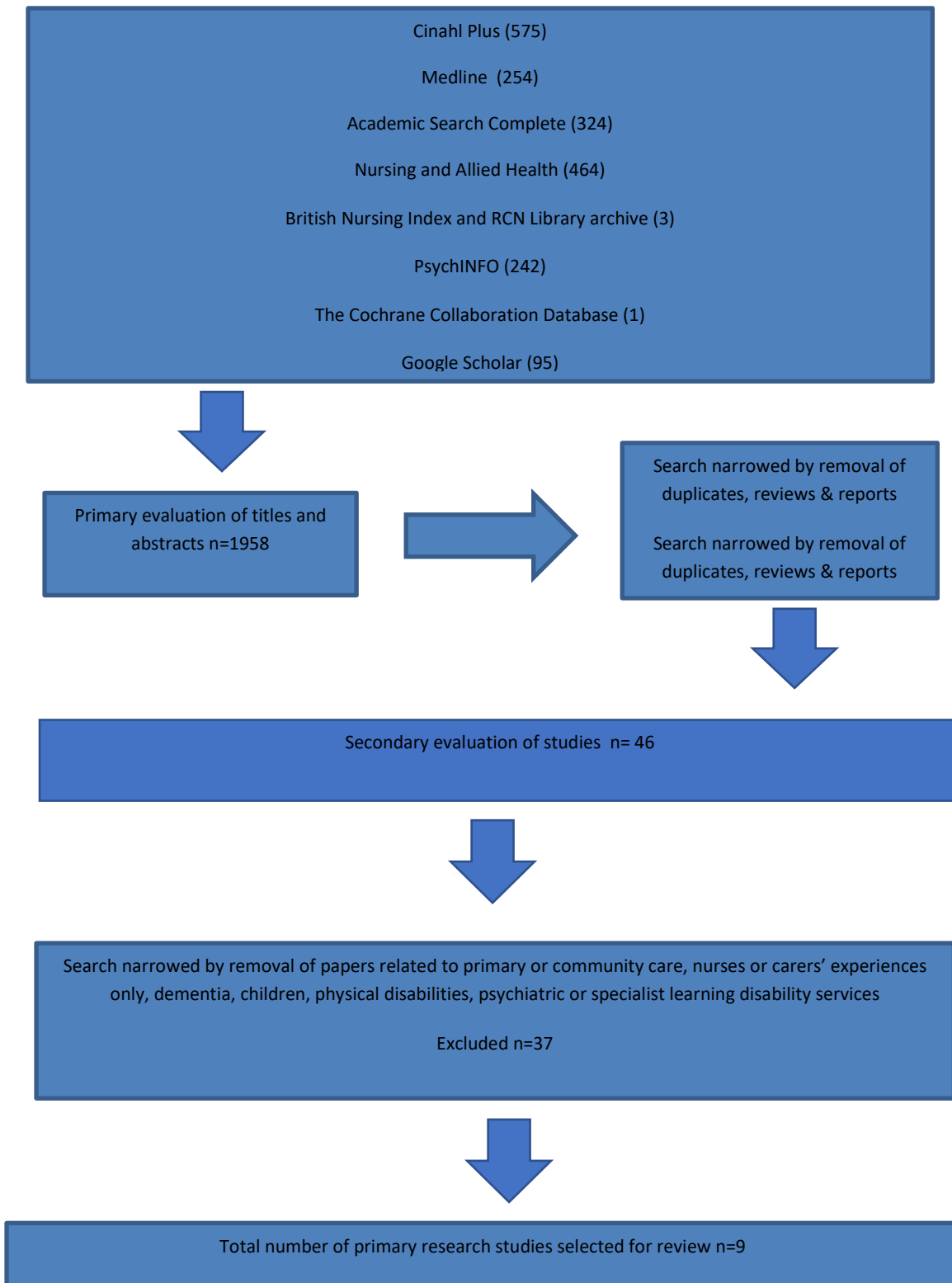
1	Learning disab* or
2	Intellectual* disab* or
3	Learning difficult* or
4	Developmental* disab* or
5	Cognitive* impair* or
6	Intellectual* impair* or
7	Mental* handicap* or
8	Mental* deficien* or
9	Mental* disab* or
10	Mental* retard* AND
11	Hospital care or
12	Secondary care or
13	Acute care or
14	Health care or
15	Orthopaedic or
16	Orthopedic or
17	Trauma or
18	Muscul*skeletal

Search outcomes

The first stage of the literature review involved the screening of all the titles and abstracts against the inclusion criteria by the first author (n=1958). Duplicates were then removed. The reviews and reports were retained and informed the background to the overall doctoral research study. The next stage involved a closer reading of the titles and the abstracts and discussions took place with all 3 authors regarding decisions about inclusion or exclusion of publications. Following this, a further number were excluded as they did not meet the inclusion criteria or were duplicates (n=1912). Some studies were related to primary or community care, nurses' or carers' experiences, dementia, children, end of life care, other disabilities rather than intellectual disabilities, psychiatric or specialist intellectual disability services rather than the general hospital experiences of adults with an intellectual disability and therefore were rejected. An evaluation of the retained full text publications (n=46) was conducted independently by the 3 authors to assess the eligibility for inclusion in the final review and consensus was reached by consultation. Reference lists were also searched to identify any further publications.

Figure 1 is a flowchart showing the process undertaken and the number of papers that each database displayed when the key search terms were used. There were nine studies that related to the general hospital experiences of PWID and therefore fulfilled the criteria for inclusion in the review. Each study was read thoroughly prior to extracting data. A quality appraisal was undertaken using validated tools developed by Kmet, Lee and Cook (2004) and Hong *et al.* (2018) prior to extracting data.

Figure 1 A flowchart showing the searches undertaken in the electronic databases



The majority of studies (n=8) adopted qualitative approaches using semi-structured interviews or focus groups as the data collection methods. One qualitative study was reported in two papers (Read *et al.*, 2018a, b) and the one mixed-methods study was reported in two papers (Tuffrey-Wijne *et al.*, 2014a, b).

Overall, there were very few studies undertaken with PWID as participants in relation to general hospital care over the period 2007-2020. This could be due to the difficulty that exists in accessing and recruiting PWID into research studies. Moreover, this area of research may not be deemed important as it has not, to the authors' knowledge, received substantial research funding. Overall, there was agreement about the poor experiences of PWID in general hospital care in the body of literature as a whole. This included a lack of concern and understanding of the individual needs of PWID and reasonable adjustments not being consistently implemented by hospital staff. These poor experiences can impact negatively on PWID who are particularly vulnerable in hospital.

There were eight studies that employed a qualitative approach with the majority, five, using semi-structured interviews and three used focus groups as the data collection method. The majority of the studies (5) were conducted in the United Kingdom (UK), two studies were conducted in the United States of America (USA) and one study was undertaken in Australia. The studies were published between 2008 and 2018.

Tuffrey-Wijne *et al.* (2014a; 2014b) undertook one of the largest studies to date focusing on the safety of PWID in acute general hospitals in the UK. This was a mixed methods study and several papers have been published from this one large study. Two of these papers were included in the review and both papers were published in 2014. The data collection methods included interviews with hospital

staff, carers and PWID, questionnaires to hospital staff and carers, observation of PWID in hospital and monitoring of incident reports. The study was conducted at six National Health Service acute hospital trusts in England, UK (Tuffrey-Wijne *et al.*, 2014a; Tuffrey-Wijne *et al.*, 2014b). The sites were purposively selected to cover a range of different hospital sizes, demographic areas and models for accessing ID expertise.

Quality appraisal

Due to the different methodological approaches adopted in the retrieved studies, they have been split according to their methodology which is a common approach to ensure the clarity of synthesis (Gray, Grove and Sutherland, 2017).

The larger number of qualitative studies indicated the appropriateness of this research approach for exploring the hospital experiences of PWID. The Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields that was developed by Kmet, Lee and Cook (2004) was adopted to appraise the qualitative studies in the final review. The Mixed Methods Appraisal Tool (MMAT) tool devised by Hong *et al.* (2018) was utilised to appraise the mixed methods study.

The appraisal tools were simple to use and included key questions related to the quality of the research methodology in each study. Tables 2 and 3 provide a summary of the appraisals for the qualitative and the mixed methods studies. The value of using the numerical rating appraisal tool was that it provided a score to indicate the quality of the study from a series of questions.

Table 2 Summary of the quality appraisal of the qualitative studies (Kmet, Lee and Cook, 2004)

Author	Question / objective sufficiently described?	Study design evident and appropriate	Context for the study clear?	Connection to a theoretical framework / wider body of knowledge	Sampling strategy described, relevant and justified?	Data collection methods clearly described and systematic?	Data analysis clearly described and systematic?	Use of verification procedure(s) to establish credibility?	Conclusions supported by the results?	Reflexivity of the account?	Score out of 20
Gibbs, Brown & Muir, 2008	Yes=2	Yes=2	Yes=2	Yes=2	Partial=1	Partial=1	Yes=2	No=0	Yes=2	Yes=2	16/20
Webber, Bowers & Bigby, 2010	Yes=2	Yes=2	Yes=2	Yes=2	Partial=1	Yes=2	Yes=2	Partial=1	Yes=2	No=0	16/20
Dinsmore 2011	Yes=2	Yes=2	Yes=2	No=0	Partial=1	Yes=2	No=0	No=0	Yes=2	Yes=2	13/20
Smeltzer, Avery & Haynor, 2012	Yes=2	Partial=1	Partial=1	Yes=2	No=0	Partial=1	Yes=2	Yes=2	Partial=1	No=0	12/20
Ali, <i>et al.</i> , 2013	Yes=2	Yes=2	Yes=2	No=0	Yes=2	Yes=2	Yes=2	No=0	Yes=2	Yes=2	16/20
Howieson, 2015	Partial=1	Partial=1	No=0	No=0	Partial=1	Partial=1	Yes=2	Yes=2	Yes=2	No=0	10/20
Gibbons, Owen & Heller, 2016	Yes=2	Partial=1	Partial=1	No=0	Partial=1	Yes=2	Yes=2	No=0	Yes=2	No=0	11/20
Read <i>et al.</i> , 2018a,b	Yes=2	Partial=1	No=0	Yes=2	Partial=1	No=0	Partial=1	Partial=1	Yes=2	Partial=1	11/20

YES (2); PARTIAL (1); NO (0)

Table 3 Mixed Methods Appraisal Tool (MMAT) version 2018 (Hong *et al.*, 2018)

The two papers below are from a single study.

Tuffrey-Wijne, I., Goulding, L., Giatras, N., Abraham, E., Gillard, S., White, S., Edwards, C., and Hollins, S. (2014a) The barriers to and enablers of providing reasonably adjusted health services to people with intellectual disabilities in acute hospitals: evidence from a mixed-methods study. *BMJ Open*. 4, 4 e004606. ISSN (online) 2044-6055

Tuffrey-Wijne, I., Goulding, L., Gordon, V., Abraham, E., Giatras, N., Edwards, C., Gillard, S., and Hollins, S. (2014b) The challenges in monitoring and preventing patient safety incidents for people with intellectual disabilities in NHS acute hospitals: evidence from a mixed-methods study. *BMC Health Services Research*. 14:432 <http://www.biomedcentral.com/1472-6963/14/432>

Category of study designs	Methodological quality criteria Responses	Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions? S2. Do the collected data allow it to address the research questions? <i>Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.</i>	Yes Yes			
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question? 1.2. Are the qualitative data collection methods adequate to address the research question? 1.3. Are the findings adequately derived from the data? 1.4. Is the interpretation of results sufficiently substantiated by data? 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	Yes Yes Yes Yes Yes			
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed? 2.2. Are the groups comparable at baseline? 2.3. Are there complete outcome data? 2.4. Are outcome assessors blinded to the intervention provided? 2.5. Did the participants adhere to the assigned intervention?				Not applicable
3. Quantitative nonrandomized	3.1. Are the participants representative of the target population? 3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? 3.3. Are there complete outcome data? 3.4. Are the confounders accounted for in the design and analysis? 3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				Not applicable
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question? 4.2. Is the sample representative of the target population? 4.3. Are the measurements appropriate? 4.4. Is the risk of nonresponse bias low? 4.5. Is the statistical analysis appropriate to answer the research question?	Yes Yes Yes	No	Can't tell	
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed method design to address the research question? 5.2. Are the different components of the study effectively integrated to answer the research question? 5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? 5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? 5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	Yes Yes Yes Yes		Can't tell	

Kmet, Lee and Cook (2004) suggest a cut-off point when scoring the studies as between 55%-75%. The scoring of the studies ranged from 10/20 (50%) indicating a poorly designed study to 16/20 (80%) indicating a well-designed study. Three studies scored 16/20 (80%), Gibbs, Brown and Muir (2008); Webber, Bowers and Bigby (2010) and Ali *et al.* (2013). Only one of the eight studies clearly referred to a theoretical framework to situate the study (Webber, Bowers and Bigby, 2010). The majority of studies (n=6) had a clear research question or objectives for the study. Only two studies provided evidence of reflexivity. All of the participants were recruited either purposively or via a convenience sample; the sample sizes ranged from 5-33 participants and the majority of the studies (n=6) included support and facilitation during data collection for the PWID by a carer. Due to the low number of studies in the review, all were retained and the numerical cut off score relating to the quality of the study was not used to eliminate them.

Data abstraction

The research papers were read several times and data were independently abstracted by one of the authors and put into a table. Table 4 has details of the title of the paper, the authors and the year the paper was published, the country of origin, the sample and sampling strategies, response rates and numbers of participants, the limitations of the study along with the key findings from each study.

Table 4 An overview of the studies included in the review in date order

Title	Author(s) and year	Country of origin	Aim / Design/ Method	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
The experiences of adults with intellectual disabilities and their carers in general hospitals: a focus group study	Gibbs, Brown and Muir 2008	Scotland UK	Aim: To explore the hospital experiences of people with intellectual disabilities Method: Qualitative Grounded theory approach using focus groups Qualitative	Purposive sample	11 adults with intellectual disabilities 9 parents 5 paid carers	The participants were drawn from a limited geographical area of South East Scotland and locality specific effects cannot be ruled out. There may have been pre-conceived biases.	Five themes emerged showing that there was a need for education and training of hospital staff in the care of people with intellectual disabilities. The themes were: feelings of fear and anxiety, communication, practicalities of being in hospital, discrimination and negative comments and behaviour problems. There were high levels of health needs and health inequalities experienced by people with intellectual disabilities.
Hospital experiences of older people with intellectual disability: Responses of group home staff and family members	Webber, Bowers and Bigby 2010	Australia	To explore the hospital experiences of older people with ID living in group homes Qualitative Grounded theory In person and telephone interviews	The managers of 13 group homes. Managers each with 4-6 residents were contacted by telephone to request they take part in the study. The group homes were managed by 7 different disability organisations	55 people were interviewed 17 residents with ID (at first interview only) together with 17 family members 16 house supervisors from the home 11 accommodation managers and 11 staff from care facilities	Some people with ID were present during the interviews with family members although few participated in the discussion due to the severity of their impairment, frailty or communication difficulties so the data was drawn from family members and care staff.	Difficulties were experienced by people with ID in hospital settings. Family and carers used extensive strategies to improve hospital experiences. Hospitals are poorly designed to care for older people with ID

Title	Author(s)and year	Country of origin	Aim Design/Method	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
A small-scale investigation of hospital experiences among people with a learning disability on Merseyside: speaking with patients and their carers.	Dinsmore 2011	England UK	Aim: To generate recommendations for enhancements to the provision of hospital care to people with a learning disability in the Merseyside area. Semi-structured interviews Qualitative study	Purposive sample	(n=12) participants overall (n=2) participants with an intellectual disability (n=3) participants with an intellectual disability and their carer present (n=7) carers	The sample size is small and the findings should not be seen as representative of the wider intellectually-disabled population. Sample method used biases the study towards participants who have had particularly positive or negative hospital experiences and also towards service users and clients of intellectual disability charities and day centre. 3 were trustees of Mencap Liverpool. Some participants described experiences that took place more than 2 years ago exposing them to a risk of recall bias. Researcher was employed by Mencap Liverpool.	PWID in Merseyside continue to face difficulties during hospital experiences as have been identified previously by national and international investigations. Eleven themes emerged from the data: Visibility of specialist intellectual disability nursing roles; Lack of awareness of provision of Annual Health checks; Placement of patients within hospital; Involvement of families and carers in the planning and provision of hospital care for PWID; Responsibilities of patient after having left hospital; Provision of medication by nursing staff; Accessibility of complaints process; Provision of accessible 'Easy Read' information about conditions, treatments and relevant legislation; Lack of awareness of patient passports; Flexibility of health care routines; Perceived staff attitudes.

Title	Author(s) and year	Country of origin	Aim Design/Method	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
Interactions of people with disabilities and nursing staff during hospitalization	Smeltzer, Avery and Haynor 2012	USA	<p>Aim: To explore the experiences of people with disabilities in their interactions with nurses and unlicensed assistive personnel and their perceptions of the care they received during hospital stays.</p> <p>Method: Qualitative approach using focus groups</p> <p>6 focus groups across 3 sites</p>	Convenience	(n=35) in total: 5 participants had intellectual disabilities	<p>Focus group methodology</p> <p>Participants with intellectual disabilities "did not fare well in the focus group" (page 36)</p>	<p>Four themes were identified: poor communication on the part of nursing staff, compromised care, negative attitudes among staff, and participants' fears related to quality of care.</p> <p>The findings suggest the need for further research into the nursing care of people with disabilities during hospitalisation. Educational strategies to ensure that nurses and unlicensed assistive personnel have adequate knowledge about the needs of people with disabilities may help in augmenting the care provided to this population.</p>

Title	Author(s) and year	Country of origin	Aim Design/Method	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
<p>Discrimination and other barriers to accessing health care: Perspectives of patients with mild and moderate intellectual disability and their carers</p>	<p>Ali, Scior, Ratti, Strydom, King and Hassiotis 2013</p>	<p>England UK</p>	<p>Aim: To examine the extent to which patients with learning disability and their carers experience discrimination or other barriers in accessing health services, and whether health care experiences have improved over the last decade Method: A qualitative approach using semi-structured interviews Qualitative</p>	<p>Eleven sites in the UK were approached- community intellectual disability services, day centres and voluntary organisations Purposive sample</p>	<p>(n=29) participants (14 patients and 14 carer dyads and one carer)</p>	<p>Almost all the carers were female and were mainly informal carers The views of people with severe and profound ID were not included Interview schedule may have limited the exploration of other issues Participants that took part may have had more health problems and more negative experiences of health care Researcher's professional and personal background shaped the analysis and interpretation of the data</p>	<p>In over half the dyads, carers and patients with ID agreed with each other in the themes and accounts that were given. A number of patients felt that they were discriminated against or treated differently because of their intellectual disability. The themes that emerged from the data were : Problems with communication Problems with accessing help Problems with how health professionals relate to carers Complexity of the health care system and lack of support for carers Substandard care of people with intellectual disability Problems with staff attitudes, knowledge and behaviour There were examples of good practice and Improvements in services : - good communication skills, friendly and helpful staff and situations where both the patient and carer felt respected.</p>

Title	Author(s) and year	Country of origin	Aim Design/Method	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
The barriers to and enablers of providing reasonably adjusted health services to people with intellectual disabilities in acute hospital: evidence from a mixed-methods study	Tuffrey-Wijne, Goulding, Giatras, Abraham, Gillard, White, Edwards and Hollins 2014a	England UK	Aim: This paper reports on the findings in relation to the following research question: 'What are the barriers to providing reasonably adjusted health services to patients with intellectual disabilities in NHS acute hospitals?' Method: mixed-methods This was a mixed-methods study in three stages, involving interviews and questionnaire surveys (July 2011– March 2013). Mixed methods	The study was conducted at six NHS acute hospital trusts in England. The sites were purposively selected to cover a range of different sizes, demographic areas and models for accessing intellectual disability expertise	Data collected included staff questionnaires (n=990), staff interviews (n=68), interviews with adults with intellectual disabilities (n=33), questionnaires (n=88) and interviews (n=37) with carers of patients with intellectual disabilities, and expert panel discussions (n=42)	The number of carers and people with intellectual disabilities participating in the study was relatively small in relation to staff participants (although the sample size was large in comparison with existing studies, and saturation of data has been achieved). Sampling of patients and carers was facilitated by the Intellectual Disability Liaison Nurse (IDLN) or Intellectual Disability Lead at each study site, leading to sampling bias and a difficulty in accessing a sample of patients and carers who had no involvement from the IDLN. The research team had no access to a sample of patients who had not been identified or flagged as having intellectual disabilities.	Hospital strategies that supported implementation of reasonable adjustments did not reliably translate into consistent provision of such adjustments. Good practice often depended on the knowledge, understanding and flexibility of individual staff and teams, leading to the delivery of reasonable adjustments being haphazard throughout the organisation. Major barriers included: lack of effective systems for identifying and flagging patients with intellectual disabilities, lack of staff understanding of the reasonable adjustments that may be needed, lack of clear lines of responsibility and accountability for implementing reasonable adjustments, and lack of allocation of additional funding and resources. Key enablers were the Intellectual Disability Liaison Nurse and the ward manager.

Title	Author(s) and year	Country of origin	Aim Design/Method	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
The challenges in monitoring and preventing patient safety incidents for people with intellectual disabilities in NHS acute hospitals: evidence from a mixed-methods study	Tuffrey-Wijne, Goulding, Gordon, Abraham, Giatras, Edwards, Gillard and Hollins 2014b	England UK	<p>Aim: To</p> <ol style="list-style-type: none"> 1. explore the challenges in monitoring and preventing patient safety incidents involving people with intellectual disabilities 2. to describe patient safety issues faced by patients with intellectual disabilities in NHS acute hospital and 3. to investigate underlying contributory factors to these safety issues. <p>Method: mixed methods study Interviews, questionnaires, observation and monitoring of incidence reports</p> <p>Mixed Methods</p>	Sample 6 acute NHS Trusts in England.	(n= 1251 in total) (n=990) clinical staff-questionnaires (n=88) carers-questionnaires (n=68) interviews with hospital staff (senior managers, nurses and doctors) (n=37) interviews with carers (n=8) Observation of in patients with intellectual disabilities (n=272) Monitoring of incident reports	A relatively low number of carers compared to hospital staff in the study.	<p>One of the largest studies to date focusing on the safety of patients with intellectual disabilities in acute general hospitals. Staff did not always readily identify patient safety issues or report them. Hospitals lacked effective systems for identifying patients with intellectual disabilities within their service which made monitoring of safety incidents for this group difficult.</p> <p>The safety issues described by participants were mostly related to delays and omissions of care, in particular inadequate provision of fundamental nursing care, misdiagnosis, delayed investigations and treatment, and non-treatment decisions along with Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders.</p> <p>Acts of omission (failure to give care) were more difficult to recognise, capture and monitor than acts of commission (giving the wrong care).</p> <p>In order to improve patient safety for PWID, the reasonable adjustments needed by individual patients should be identified, documented and monitored.</p>

Title	Author(s) and year	Country of origin	Aim Design/Method	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
Experiences of acute hospital services among people with mild to moderate learning disabilities	Howieson 2015	Scotland UK	Aim: To explore the experiences of acute hospital services of PWID Method: qualitative approach using 2 focus groups Qualitative	Paper does not discuss how participants were recruited	(n=7) participants with mild or moderate intellectual disabilities Participants had accessed an acute hospital in the last 12 months	The study was small and undertaken in one part of Scotland, UK Strength- the focus groups were facilitated by an advocate and a researcher	Themes from IPA analysis were: Treat me right, with subordinate themes of: Valuing people, dignity, respect, and therapeutic relationships. Hidden in plain sight, with subordinate themes of: Accountability, staff attitude and vulnerability. Health care for all, with subordinate themes of: Inappropriate communication systems, inaccessible information and the environment. The findings resonate with current literature and add to the growing body of knowledge relating to acute hospital services and the needs of PWID.

Title	Author(s) and year	Country of origin	Aim Design/methods	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
Perceptions of Health and Healthcare of people with intellectual and developmental disabilities in Medicaid Managed Care	Gibbons, Owen and Heller 2016	USA	<p>Aim: To examine the perceptions of health and healthcare of people with intellectual and developmental disabilities receiving Medicaid Managed Care.</p> <p>Qualitative Method: Exploratory semi-structured telephone interviews</p>	<p>Sample: (n=23) participants with various level of intellectual and developmental disability</p> <p>Purposive sample</p>	23 participants volunteered	<p>Telephone interview with people with intellectual and developmental disabilities- who were verbal therefore excluded people with severe impairments</p> <p>Small study</p> <p>Study only included people in Medicaid Managed Care in USA- who self-identified as having an intellectual and developmental disability.</p> <p>It is unclear if the participants had experience in acute hospital care settings as primary care and specialist care is stated. However, the study was included as PWID expressed what they valued and want from providers of health care.</p>	<p>Important implications for health care providers within the Medicaid Managed Care system in USA.</p> <p>The themes that emerged from the data were the importance of being treated with respect and dignity, the value of relationships with their health care providers, having medical staff who could communicate clearly, there was confusion around care coordination and a need for accessible information on care coordination.</p>

Title	Author(s) and year	Country of origin	Aim Design/methods	Sample and Sampling strategy	Response rate (%) and participant numbers (n=)	Limitations	Key findings
Being a Disabled Patient: Negotiating the Social Practices of Hospitals in England	Read, Williams, Heslop, Mason-Angelow and Miles 2018a	UK	Aim: To understand disabled people's experiences of how they interact with, and are affected by, existing hospital practices Qualitative Semi-structured interviews	Convenience sample. Participants volunteered who self-identified as disabled	n=21	It is unclear how many participants had an intellectual disability in the study	Disability-related needs were often invisible despite the legal protections in place and ignored within the hospital system. A major issue for disabled patients was the need to repeatedly advocate for themselves and explain their needs to staff. Problems arise when things are designed in such a way that disabled people are forced to confront their difference, and to make that difference visible to others. This can become a problem in itself, resulting in disabled patients feeling guilty, anxious or frustrated. The Equality Act (2010) legislation, intended to mitigate or remove disabling practices seems to have had little impact on day-to-day hospital experiences.
Disabled people's experiences of accessing reasonable adjustments in hospitals: a qualitative study	Read, S., Heslop, P., Turner, S., Mason-Angelow, V., Tilbury, N., Miles, C., and Hatton, C. 2018b	UK	Aim: To present the perspectives of disabled people in relation to their experiences of accessing reasonable adjustments in hospitals in England. Qualitative Semi-structured interviews	Convenience sample. Participants volunteered who self-identified as disabled	n=21	It is unclear how many participants had an intellectual disability in the study as it had a pan disability approach.	Five themes relating to reasonable adjustments to the hospital care disabled people received were identified from the interview data: (i) the process of identifying a person's need for reasonable adjustments; (ii) reasonable adjustments in relation to the physical features of a hospital; (iii) changes to existing practices within a hospital; (iv) the provision of additional aids or services; and (v) recommendations for the provision of reasonable adjustments for disabled people by hospitals. The provision of reasonable adjustments by hospitals for disabled people is a significant issue requiring future research.

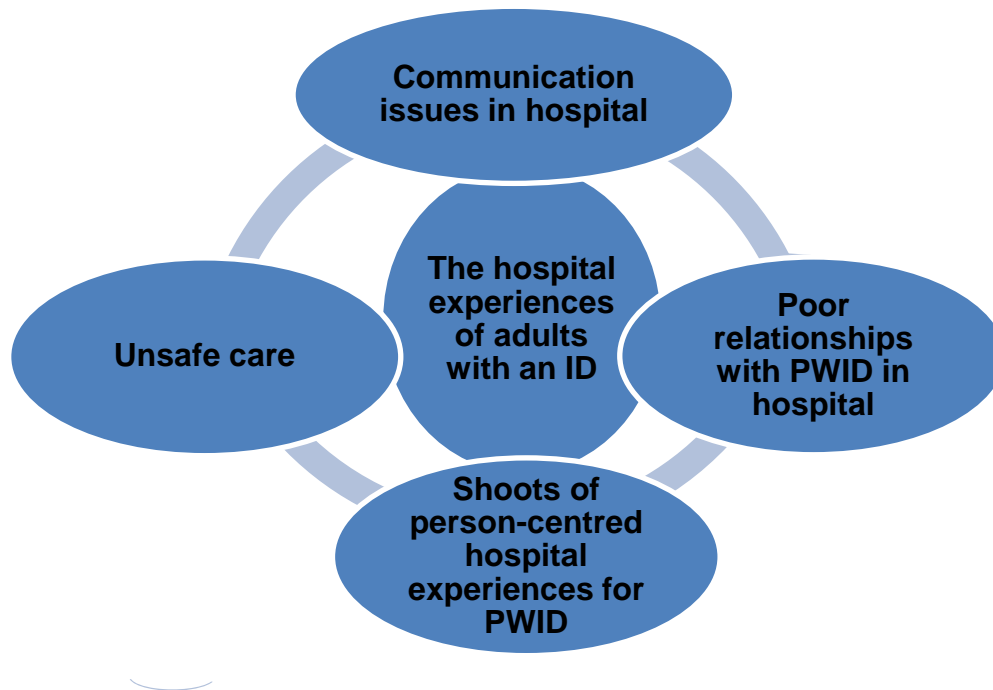
Synthesis

Synthesis of the studies involved clarifying the meaning obtained from the sources as a whole (Gray, Grove and Sutherland, 2017). When the methodological critique was completed, each study was read again several times before initial codes were generated and then themes were extracted, reviewed and then named relating to the hospital experiences of adults with ID. The themes were derived by undertaking a constant comparative analysis (Lincoln and Guba, 1985).

RESULTS

All 3 authors agreed on the final four overarching themes: communication issues in hospital; unsafe care; poor relationships with PWID in hospital and shoots of person-centred hospital experiences for adults with ID; these were derived from the subthemes and initial codes. The four themes were inter-linked and illustrate the reported general hospital experiences of adults with ID. All three authors independently developed and agreed the initial codes, subthemes and verified the overall themes. Figure 2 shows the over-arching themes from the studies.

Figure 2 The overarching themes from the studies



Theme 1: Communication issues in hospital

All nine studies highlighted that there were communication issues for PWID in hospital. Two subthemes, 'increased fear and anxiety due to poor communication' and 'a lack of person-centred communication' emerged from the initial codes and formed the main theme, 'communication issues in hospital'. The following quotations illustrate this theme:

the doctor did most of the talking because I told him I was a bit scared but the doctors didn't give me time to speak, didn't give me time to explain it, I feel better if they would give me more time to explain things, they done all the talking they wrote all the drawings on your file and all that they didn't sort of explain things properly (Gibbs, Brown and Muir, 2008).

It's like, (they) come into your room for just a second and they talk to you sometimes like you're a five year old (Ali et al., 2013).

Subtheme 1.1: Increased fear and anxiety due to poor communication

The study conducted by Gibbs, Brown and Muir (2008) was one of the strongest methodologically in this review and investigated the experiences of PWID in general hospitals. Focus groups were used to collect information from PWID (n=11) who had been in hospital within the previous year and their carers (n=14). All participants (n=25) very commonly described feeling anxious and fearful. The consequences of anxiety and fear can be detrimental for all patients, but for PWID it can result in behavioural disturbance and have a negative influence on subsequent care (Tuffrey-Wijne *et al.*, 2016). Both the patients and the carers were anxious about investigations, injections, procedures, operations and situations involving other patients. Dinsmore (2011), Webber, Bowers and Bigby (2010) and Gibbs, Brown and Muir (2008) concur in that there was a failure of hospital staff to communicate effectively with other staff regarding PWID in their investigation findings. Alongside this, PWID were fearful about having their assistive devices taken away from them in hospital as these aided their communication, and in essence acted as their expressive 'voice' (Smeltzer, Avery and Haynor, 2012).

Subtheme 1.2: A lack of person-centred communication

Problems with communication were discussed by 12/14 PWID in the study by Ali *et al.* (2013). Hospital staff did not modify or adapt communication to their needs and examples were relayed such as, asking too many questions, speaking too quickly, giving too much information and not giving PWID time to respond. Furthermore, hospital passports, which contain key information about a PWID were not used (Dinsmore, 2011). Similarly, Webber, Bowers and Bigby (2010) found that key

information from carers, which could support staff in caring for PWID, was not used by staff in hospital and instead, information methods that were inaccessible for PWID were employed (Ali *et al.*, 2013; Howieson, 2015; Read *et al.*, 2018a; Read *et al.*, 2018b). Alongside this, some hospital staff spoke to the carers instead of the PWID (Gibbs, Brown and Muir, 2008).

Theme 2: Unsafe care

All nine studies discussed aspects of hospital care that resulted in unsafe care for PWID. The subthemes, 'lack of reasonable adjustments' and 'fundamental care omissions and mistakes' were formed from the initial codes and the overall theme, 'unsafe care' was developed. The following quotations illustrate this theme:

he wouldn't even get me any water.
(Dinsmore, 2011)

I sneaked off and got a drink. See we were forgotten...three hours later they still ain't coming with my coffee...it happens quite a lot sometimes. If I was a normal person I'd get treated a bit better, like a proper person.
(Tuffrey-Wijne *et al.*, 2014a)

Subtheme 2.1: Lack of reasonable adjustments

Hospital strategies that supported implementation of reasonable adjustments did not reliably translate into consistent provision of such adjustments (Tuffrey-Wijne *et al.*, 2014a; Read *et al.*, 2018b). Good practice often depended on the knowledge, understanding and flexibility of individual staff and teams, leading to inconsistency in the delivery of reasonable adjustments throughout the organisation. Tuffrey-Wijne *et al.* (2014a) found that the major barriers to implementing reasonable adjustments included:

lack of effective systems for identifying and flagging PWID; lack of staff understanding of the reasonable adjustments that may be needed; lack of clear lines of responsibility and accountability for implementing reasonable adjustments; and lack of allocation of additional funding and resources. Similarly, Ali *et al.* (2013) and Howieson (2015) found that reasonable adjustments such as using pictures, large print and easier read information were not implemented in hospitals.

Tuffrey-Wijne *et al.* (2014a) reported on the findings in relation to the barriers to providing reasonably adjusted health services to PWID in NHS acute hospitals. The study employed interviews and questionnaire surveys from July 2011–March 2013. Data collected included staff questionnaires (n=990), staff interviews (n=68), interviews with PWID (n=33), questionnaires (n=88) and interviews with carers of PWID (n=37) and expert panel discussions (n=42). The number of PWID participating in the study was relatively small in relation to staff participants although the sample size was large in comparison with existing studies and the researchers believed that saturation of data had been achieved.

Sampling of patients and carers was facilitated by the ID liaison nurse or ID Lead at each study site, leading to sampling bias which could have been reduced if the selection of patients and carers had been undertaken in a more randomised way. The research team had no access to a sample of patients who had not been identified or flagged as having ID.

Subtheme 2.2: Fundamental care omissions and mistakes

Ali *et al.* (2013) conducted semi-structured interviews to examine the extent to which PWID and their carers' experiences of health care had improved over the last decade. Some of the findings were particularly concerning as they included the prescription of incorrect medication, investigations and treatments being delayed or lacking altogether. Moreover, there were reports of neglect of basic needs on hospital wards including a lack of support to use the toilet.

Webber, Bowers and Bigby (2010) highlighted that the greatest concerns expressed from family members and carers were around eating and elimination needs as PWID in hospital were often unable to access food which was left unopened and uneaten. Furthermore, there was inadequate pain assessment along with carers noting that PWID who were continent had incontinence pads applied in hospital (Webber, Bowers and Bigby, 2010).

Tuffrey-Wijne *et al.* (2014b) aimed to explore the challenges in monitoring and preventing patient safety incidents involving PWID, to describe patient safety issues faced by PWID in NHS acute hospitals and to investigate underlying contributory factors to these safety issues. Tuffrey-Wijne *et al.* (2014b) found that patient safety issues were mostly related to delays and omissions of care, in particular inadequate provision of fundamental nursing care, misdiagnosis, delayed investigations and treatment, non-treatment decisions along with 'DNACPR' orders. However, acts of omission (failure to give care) were more difficult to recognise, capture and monitor than acts of commission (giving the wrong care). Furthermore, staff did not always identify safety issues for

PWID or report those and monitoring of safety incidents for PWID was difficult (Tuffrey-Wijne *et al.*, 2014b).

Similarly, Ali *et al.* (2013) highlighted the substandard care of PWID in hospital, such as inadequate follow-up, incorrect medication, unnecessary investigations or investigations and treatments being delayed, inadequate discharge arrangements along with a lack of support with toileting needs. Alongside this, Webber, Bowers and Bigby (2010) reported the early inappropriate discharge of PWID from hospital and care home staff unable to continue the level of care needed.

Theme 3: Poor relationships with PWID in hospital

All nine studies highlighted concerns relating to the relationships formed by health care staff with PWID in hospital settings. There were two subthemes that emerged from the initial codes, 'lack of caring and understanding for the individual PWID' and 'perceived discrimination towards PWID' which resulted in the overall theme, 'poor relationships with PWID in hospital'. The following quotations illustrate this theme:

*A couple of times on [the ward] I tried to get their attention, I was in pain and needed medication. I had to get my mum to speak to them and she had to complain, saying I need medication for my pain (Tuffrey-Wijne *et al.*, 2014b).*

I don't like needles you see, I can't stand needles and I even remember crying and screaming for me mum and they wouldn't get me mum, they just took me straight down. They did it but I told them not to do it, and I was screaming and crying but they wouldn't have it, they said 'it's got to be done Pat' and all this, but I said I want me mum and they wouldn't get me mum and they just left me. I still would've been screaming and crying but me mum would've calmed me down (Dinsmore, 2011).

Subtheme 3.1: Lack of caring and understanding for the individual PWID

Accounts of negative hospital staff behaviour along with a lack of support for and involvement of PWID and their carers were evident in the majority of the studies (Ali *et al.*, 2013; Gibbs, Brown and Muir, 2008; Gibbons, Owen and Heller, 2016; Howieson, 2015 and Read *et al.*, 2018a; Read *et al.*, 2018b). Webber, Bowers and Bigby (2010) highlighted that staff incorrectly assumed that PWID were unable to understand and therefore did not provide information that might have helped them during their hospital stay. Hospital staff were reported to have poor knowledge about PWID which led to PWID being left on their own in hospital (Webber, Bowers and Bigby (2010).

Subtheme 3.2: Perceived discrimination towards PWID

Participants with mild-moderate ID who were part of a focus group in the study conducted by Howieson (2015) felt disrespected and not valued during their acute hospital experiences. This appeared to be related to a lack of reasonable adjustments to the communication methods used by hospital staff. Dinsmore (2011) also found that the hospital experiences of PWID and carers remain poor and it was not possible to assert that the recommendations of the reports produced after Death by Indifference, 'Valuing People Now' and 'Healthcare for All' were being acted upon by health care staff. There were PWID who continued to contest with the same difficulties during hospital experiences as have been identified previously by numerous national investigations.

Smeltzer, Avery and Haynor (2012) found there was poor communication on the part of nursing staff, compromised care and negative attitudes among staff towards PWID. A

more recent study by Read *et al.* (2018a, b) demonstrated that disabled people felt their unique needs in hospital were not addressed or accommodated.

Theme 4: Shoots of person-centred hospital experiences for PWID

Although this theme appears contradictory to the previous themes, four out of nine studies reported some positive person-centred hospital experiences for PWID (Ali *et al.*, 2013; Howieson, 2015; Gibbons, Owen and Heller, 2016; Read *et al.*, 2018b). This theme had the least number of studies supporting it and although the study conducted by Howieson (2016) was the weakest methodologically, the study by Ali *et al.* (2013) was one of the highest scoring studies methodologically. One subtheme emerged from the initial codes: 'evidence of reasonable adjustments made in practice' which then formed the overall theme of, 'Shoots of person-centred hospital experiences for PWID'.

The following quotations illustrate this theme:

[My doctor] is concerned about [my] situation, and tries to help the best that she can, gives me excellent help.
(Gibbons, Owen and Heller, 2016)

Staff were nice enough. Before, they put a mask on me, I don't like the mask, so they put the jag [injection] in my hand. (Howieson, 2015)

Subtheme 4.1: Evidence of reasonable adjustments made in practice

In the study by Ali *et al.* (2013) there were examples of good practice and improvements to hospital services as 12/14 PWID and 13/15 carers reported examples of good practice which included good communication skills, friendly and helpful staff and the incorporation of reasonable adjustments, such as longer appointment times which

catered for the individual needs of PWID. In the study conducted by Howieson (2015) two out of seven participants had good hospital experiences as they felt that nurses and doctors explained what was happening and they could understand this. The study by Gibbons, Owen and Heller (2016) was undertaken in the USA and specifically related to Medicaid Managed Care where the participants shared what good health care meant to them via an exploratory, semi-structured telephone interview. This included having a good relationship with medical providers, being treated as an individual and receiving personalised care when doctors listened, demonstrated concern and exhibited patience. One participant with intellectual disabilities in the study conducted by Read *et al.* (2018b) described a positive experience of a health professional reviewing her hospital passport with her, commenting that *'it's good having it'* to ensure that the staff understood her needs.

Table 5 shows a summary of the overall themes that were derived from the research papers that were included in the IR.

Table 5 A summary of the themes derived from the research studies.

Themes Author(s) & Date	Communication issues in hospital	Unsafe care	Poor relationships with PWID in hospital	Shoots of person- centred hospital experiences for PWID
Gibbs, Brown and Muir (2008)	✓	✓	✓	✗
Webber, Bowers and Bigby (2010)	✓	✓	✓	✗
Dinsmore (2011)	✓	✓	✓	✗
Smeltzer, Avery and Haynor (2012)	✓	✓	✓	✗
Ali <i>et al.</i> (2013)	✓	✓	✓	✓
Tuffrey-Wijne <i>et al.</i> (2014a, b)	✓	✓	✓	✗
Howieson (2015)	✓	✓	✓	✓
Gibbons, Owen and Heller (2016)	✓	✗	✓	✓
Read <i>et al.</i> (2018a,b)	✓	✓	✓	✓

DISCUSSION

The majority of the studies in this review adopted a qualitative approach to explore the perspectives of adults with ID who had previous experience of hospital care. All of the studies demonstrated that the experiences of hospital were poor overall with the potential for serious health consequences. There was a link between the themes identified, for example, poor communication can have a negative impact upon people's experiences of hospital care. In some studies, carers and family members were participants alongside the adults with ID and contributed to the data collection which may have influenced the voice of the person with ID. It was unclear in all of the studies whether adults with ID received alternative or additional support or were offered the use of communication aids to help them to share their experiences. The majority of the qualitative studies included the carers' perspectives too and it is accepted and

understood that for some adults with ID, the carers are needed to facilitate the discussion during the interview or focus group.

The standards of hospital care were of concern due to the potential for serious morbidity and mortality and this concurs with Heslop *et al.* (2013) Confidential Inquiry into Premature Deaths of People with a Learning Disability (CIPOLD). It was recognised that PWID have greater health care needs due to multiple co-morbidities. There were concerns about poor communication, unsafe care and poor relationships with PWID in hospital. Furthermore, fundamental care was omitted, delayed and mistakes were made, all of which could lead to the subsequent development of complications that are preventable in hospital.

Although inconsistent, there were participants in four studies who highlighted areas where their experiences of being in hospital were positive. It was encouraging that this theme emerged in the later studies in the review which may indicate that some positive changes in hospital practices have been implemented since the report, 'Death by indifference (Mencap, 2007), or simply that these studies incorporated questioning regarding the more positive aspects of care people had experienced.

Limitations

A possible limitation of the review was the exclusion of systematic reviews as they did not meet the inclusion criteria; the focus was on primary research studies which included PWID as participants. Although an integrative review does not adopt the rigor of a systematic review, a structured and comprehensive process was followed. There

was a narrow pool of research studies in the final review and they all had methodological weaknesses and therefore results should be viewed with caution. That said, the review provides new insights into an under researched area. The participants in the studies conducted by Smeltzer, Avery and Haynor (2012) and Read *et al.* (2018 a; b) were people with various disabilities which included PWID. Despite this, all the studies were retained because they provided evidence of the experiences that PWID and their carers have shared about their care in general hospitals.

Although studies were identified from a range of countries, the review was restricted to publication in the English language as there was no funding for translation services therefore there might be studies available in another language that were not accessed. Finally, as there were no studies in the review that attempted to include the 'hidden majority' of PWID who remain unknown to intellectual disability services (Emerson, 2011), this presents a gap in the research literature as all participants within the studies were known to ID services at the time they entered hospital. The hidden majority are PWID who self-identify as having an intellectual disability but may not be receiving or known to services.

The strengths of this review were the use of a systematic and replicable search for empirical studies over a period of 13 years, from 2007- 2020. Quality appraisal tools were used to assess the strength of the methodology of each study. A rigorous approach was undertaken to interpret the collective findings from the studies to enable

synthesis and evaluation of the pool of studies about PWID who have experienced hospital care.

CONCLUSION

The experiences of patients have increasingly been used to assess, plan and implement changes in service provision and policy development (Lees, 2011) and forms one of the cornerstones of evidence-based practice for health care practitioners (Sackett *et al.*, 1996). The majority of PWID had poor experiences of hospital care despite numerous policies, guidelines and legislation in place to counteract this. However, there were no published empirical studies available to the authors' knowledge that related to orthopaedic or trauma hospital experiences specifically, despite PWID having a greater prevalence of conditions and injuries affecting the musculoskeletal system (Kinnear *et al.*, 2018).

The review has identified a gap in the current research literature and a need for robust and rigorous research studies examining the question, 'How do adults with an intellectual disability describe their orthopaedic or trauma hospital experiences?'

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