**Experiences of adults with intellectual disabilities accessing acute hospital services: A systematic review of the international evidence.**

**Abstract**

Adults with intellectual disabilities experience significant physical and mental health needs when compared to the typically developing. Previous research evidences that many people with intellectual disabilities have negative encounters within acute hospitals. The aim of this systematic review was to identify the specific views and experiences of adults with intellectual disabilities when accessing acute hospital services arising from the available literature. The review commenced in June 2019 and updated in May 2020. A systematic search of five electronic databases including CINAHL Plus, MEDLINE, Web of Science, SCOPUS and PsycINFO) was undertaken. Studies published from 2014, peer-reviewed, written in English and referred to adults with intellectual disabilities aged 18 plus and acute hospital settings were included. The PRISMA guidelines and the CASP quality assurance checklist were used to review all selected papers. Five studies from a total of 421 were deemed suitable for inclusion in the review as the voices of adults with intellectual disabilities were present. Poor communication from healthcare staff towards adults with intellectual disabilities emerged in four studies while the use of the hospital passport and the intellectual disability liaison nurse to significantly improve the hospital experience for adults with intellectual disabilities was identified in two of the studies. Following a systematic and thematic analysis of the studies, three main overarching themes emerged: communication; information sharing; and compassion and respect. Despite the national and international focus on improving healthcare for people with intellectual disabilities, this review highlights lack of communication, inadequate information sharing, and issues related to compassionate care and respect. The review identifies the possibility that an increased use of hospital passports and an extension of the intellectual disability liaison nursing roles may enhance the hospital experience for people with intellectual disabilities.

**KEYWORDS**

adult, experience, hospital, intellectual disability, learning disability

**What is known about this topic**

* People with an intellectual disability are twice as likely to access general hospitals when compared to the general population.
* There is some evidence of Hospital Passports being used in a variety of healthcare settings but there is a lack of consistency in its application.
* Studies tend to focus on the experiences of healthcare professionals.

**What this paper adds**

* Provides an insight from the perspective of adults with intellectual disabilities when accessing acute hospital services.
* Healthcare professionals still appear to lack knowledge or awareness of people with intellectual disabilities resulting in poor communication and information sharing.
* The experience of people with intellectual disabilities can be improved when staff use the Hospital Passport appropriately.

**1 BACKGROUND**

Research evidence highlights that almost 2% of the world population have an intellectual disability (Public Health England, 2016). It is anticipated that the population will increase in the coming decades as a result of a number of factors, including the increasing childhood survival rates, improved diagnosis, autism screening and identification of mortality figures (RQIA, 2016). An ageing population is a transnational demographic phenomenon with social, economic and political implications (World Health Organisation, 2016). Over the past century, the life expectancies for the general population has increased dramatically. Similarly, across many western countries, the life expectancy of people with an intellectual disability have significantly increased (Braddock, et al., 2001). Moreover, adults with an intellectual disability age earlier compared to the non-disabled, with ageing commencing earlier at 50 years and for people with Down syndrome at 40 years (Bittles, et al., 2002).

 Due to their range of complex needs, including health conditions, people with intellectual disabilities are twice as likely to access general hospitals when compared to the general population. The factors effecting healthcare access and utilisation include, higher rates of and vulnerability to specific health conditions, increasing longevity and conditions associated with ‘old age’, collectively resulting in the increasing ‘complexity’ of health needs (RQIA, 2018). In contrast with the typically developing, conditions leading to admission include injuries and falls, diabetes, respiratory problems, chest pains and epilepsy (Castles et al., 2014; Drozd & Clinch, 2016; Harris & Sheehan, 2017). However, adults with intellectual disabilities are more likely to have an increased frequency of hospital admissions, longer stays and require additional and often significant support from carers or hospital staff (Drozd & Clinch, 2016; Iacono et al., 2014). Yet, as frequent users of acute hospital services, care provision for adults with intellectual disabilities at times falls short of acceptable standards (Michael, 2008; Heslop et al., 2013a; Heslop et al., 2013b). Some of the common concerns cited for suboptimal care include a lack of knowledge or skills by healthcare professionals regarding the distinct needs of adults with intellectual disabilities (Backer et al., 2009; Heslop et al., 2013a; Heslop et al., 2013b), communicating difficulties (Ali et al., 2013; Bell, 2012), confidence and a lack of knowledge of legislation that requires service providers, including acute hospitals, to consider and accommodate *‘reasonable adjustments’* to improve health outcomes (MacArthur et al., 2015). More often, healthcare staff are not informed that the patient they are supporting has an intellectual disability (Tuffrey-Wijne et al., 2014b; Heslop et al., 2013b) and as a consequence care is often adversely affected until healthcare staff are informed by family carers and community-based colleagues.

 There is a growing body of evidence-based research exploring the experiences of healthcare professionals (Applegren et al., 2018; Drozd & Clinch, 2016; Lewis et al., 2017; Ndengeyingoma & Ruel, 2016), and dentists (Nagarajappa et al., 2013; Perusini et al., 2016; Shield et al., 2013) when supporting adults with intellectual disabilities. A recurring theme is the need for a better understanding of expectations and how to communicate effectively with adults with intellectual disabilities highlighting the need for specific policies, clinical guidelines and education. Additionally, an increase in research involving families and carers of adults with intellectual disabilities is also evident (Charles, 2020; Dinsmore, 2011; Williamson & Meddings, 2018). There is a desire by family and carers to have essential care information proactively disseminated to hospital professionals caring for the adult with intellectual disability. There is also uncertainty regarding the family and carer contributions to care during hospital admission. A systematic review of 16 studies published between 2009 and 2013 of the acute hospital experiences of both people with intellectual disabilities and their carers was carried out by Iacono et al. (2014). This review concluded that people with intellectual disabilities continue to have poor hospital experiences. Drozd et al. (2020) in their integrative review of nine studies published between 2008 and 2018 also identified communication issues, unsafe care and poor relationships with people with intellectual disabilities when in hospital. Whilst the topics in their paper are somewhat related to this systematic review, they do not exclusively relate to the experience of the adult with intellectual disabilities in an acute hospital setting.

Indeed, the literature that does exist, presents a picture of poor quality healthcare and health outcomes (Heslop et al., 2013a; Iacono et al., 2014). The experiences of adults with intellectual disabilities receiving hospital care has been the subject of attention, highlighting negative experiences and outcomes (The Learning Disabilities Mortality Review (LeDeR), 2018). Reasons include poor clinical care, failure to make reasonable adjustments, diagnostic overshadowing, poor management of pain, inadequate training for staff and poor coordination of care; and have all contributed to the avoidable deaths of people with intellectual disabilities whilst in acute hospital care (LeDeR, 2018; MENCAP, 2007). Further, the confidential inquiry into the premature deaths of 247 children and adults with intellectual disabilities highlighted the need for changes to be made in the provision of healthcare for people with intellectual disabilities as a matter of urgency (Heslop et al., 2013a). Despite numerous exemplar reports (MENCAP, 2007; Michael, 2008; MENCAP, 2012; Care Quality Commission, 2012; Heslop et al., 2013a), guidance documents (GAIN, 2010; RQIA, 2018) and current legislation (Disability Discrimination Act, 1995; Equality Act, 2010), there remains a lack lustre approach to the care of people with intellectual disabilities when attending hospitals and accessing general healthcare services (World Health Organisation, 2018).

 Therefore, the aim of this systematic review was to identify the explicit views and experiences of adults with intellectual disabilities accessing acute hospital services. This was to explore if experiences have indeed remained the same or improved for adults with intellectual disabilities following on from recommendations arising from previous research. The scope of the review is limited to 2014 onwards as literature prior to that time would have been included in Iacono et al’s. (2014) review.

**2 METHODS**

**2.1 Search strategy**

This systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2015). The review commenced in June 2019 and updated in May 2020. Five electronic databases (CINAHL Plus, MEDLINE, Web of Science, SCOPUS and PsycINFO, and Sociological Abstracts) were systematically searched to identify eligible studies. Reference lists of all relevant studies were also reviewed. The results of each search were imported onto the EndNote software and merged with duplicates of the same article subsequently being removed.

 Whilst the term ‘intellectual disability’ is used globally and listed as a MeSH term (medical subject headings), ‘learning disability’ is also adopted in the UK (Emerson & Heslop, 2010). Therefore, a search for both terms was conducted using the Boolean operator ‘OR’. The search terms used were as follows: intellectual disabilit\* OR learning disabilit\* AND hospital\* AND experience. Where intellectual disability was not available as a MeSH term, ‘intellectual disabilit\*’ was used. Independent searches were completed by the first and second authors (XX and XX removed for peer review) and cross checked by each other. This systematic review was limited to articles published since 2014 following previous research by Iacono et al. (2014). Studies were limited to academic peer-reviewed research papers written in the English language. A subject Librarian assisted with the literature searching.

 An example of the search strategy, and results, used in PsychINFO one of the electronic databases is presented in Table 1. This strategy was also adapted for the other four databases. An example of a full search string used in SCOPUS is presented in Appendix A.

**INSERT TABLE 1**

**2.2 Study screening and selection**

The first and second author (XX removed for peer review) appraised all studies by title and abstract, to determine eligibility for inclusion and to remove irrelevant studies based on inclusion and exclusion criteria. The inclusion criteria were limited to adults with intellectual disabilities aged 18 years plus and acute hospital settings. Studies that focused on other healthcare settings, adults without intellectual disabilities, children or young people were excluded. This review considered all studies which included qualitative, quantitative, mixed-methods approaches and systematic reviews.

 Discussion with the wider research team resolved any discrepancies in the ongoing selection of studies to ensure that only adults with intellectual disabilities and acute hospital settings were included. Full-text papers of potentially relevant studies were then retrieved for further exploration. Reference lists were also reviewed.

**2.3 Data extraction**

Data extraction was completed by the first author and checked for accuracy by the second author. Extracted data included the study citation (i.e. author name and year of publication) and country; aims of the study; sample size (i.e. number of people with intellectual disabilities and age range where available); study setting; data collection methods; key findings; and recommendations. Data are presented in Table 2.

**INSERT TABLE 2**

**2.4 Quality assessment**

The Critical Appraisal Skills Programme (CASP) was used to assess the quality of the selected papers (Critical Appraisal Skills Programme, 2013). Each paper was scored by the first author against ten questions (Table 3). Each question was scored zero, one or two, enabling a total maximum score of 20 (Rushbrooke et al., 2014). A zero score was assigned where the information was not mentioned; where information was partially explicit a score of one was given; and where the information was fully explicit a maximum of two points were awarded. The assessment included the risk of bias with points not being awarded where research relationships and ethical issues were not considered, and an appropriate recruitment strategy was not evident. The scores were checked by the second author and any discrepancies were resolved through discussion.

 Two studies demonstrated a high quality overall achieving a maximum score of 20 (Tuffrey-Wijne et al., 2014a; Tuffrey-Wijne et al., 2014b). A lower score of 10 was achieved by the remaining three studies (Howieson, 2015; Phillips, 2019; Walker et al., 2014) as the detail required by many of the questions were not explicit or were only partially detailed. Following quality appraisal, all five studies were included as they met the objectives of the review.

**INSERT TABLE 3**

**3 RESULTS**

A total of 421 articles were identified from the search of the five databases. A total of 186 duplicates and irrelevant documents were removed with the assistance of the EndNote software and personal checks. The selection criteria were applied to the titles and abstracts of the remaining 235 articles. Following the application of inclusion and exclusion criteria, a total of 24 articles were identified as potentially relevant and full-text papers were scrutinised. The reference lists of these studies were reviewed, and three additional studies were identified. Following scrutiny of the full-text articles, 22 were excluded as they did not meet the inclusion criteria, they were not representative of adults with intellectual disabilities or of an acute hospital experience. A total of five studies were deemed eligible and agreed with the wider research team for inclusion in the study. These studies were independently screened by two reviewers (XX and XX removed for peer review). Although this was an international review of the literature, only papers from the UK were included. This could be attributed to disability nursing being retained as a clinical specialty in the UK Nursing and Midwifery register with other countries such as Australia combining the areas of disability and rehabilitation to include brain injury and stroke (Lewis et al., 2017).

 A flow chart showing the utilisation of the PRISMA guidelines (Moher et al., 2015) at the identification, screening, eligibility and inclusion stages and showing the results of the searches is presented in Figure 1.

**INSERT FIGURE 1**

 A descriptive summary of each of the five included studies is presented in Table 2. All five studies were conducted in the UK and were qualitative in design. The study settings were acute hospitals in England, Scotland and Wales and included a surgical ward and outpatients. A variety of data collection methods were used which included focus or small discussion groups (Howieson, 2015; Walker et al., 2014), semi-structured interviews (Tuffrey-Wijne et al., 2014a; Tuffrey-Wijne et al., 2014b) and a case study (Phillips, 2019).

 The sample size of participants who were adults with intellectual disabilities within each study ranged from 1 to 33. Three studies drew from participants across healthcare staff and family/carers in addition to people with intellectual disabilities. One of the selected studies (Howieson, 2015) focused solely on seven adults with mild to moderate intellectual disabilities, with one other (Phillips, 2019) reporting on a case study of an adult with intellectual disability. Collectively the studies provided information on the experiences of 104 adults with intellectual disabilities accessing acute hospital services since 2014 (it is recognised that the same 33 participants may be included in two of the included studies).

 All studies examined the experiences of people with intellectual disabilities when accessing acute hospital services. Two of the studies reported issues with making reasonable adjustments (Phillips, 2019; Tuffrey-Wijne et al., 2014b), with one other reporting challenges for people with intellectual disabilities in relation to patient safety incidents (Tuffrey-Wijne et al., 2014a). A thematic analysis of the data across all five studies was undertaken. Emergent themes were identified and then discussed with and verified by the research team (Caldwell et al., 2011). Three main themes emerged following the systematic analysis of the studies: communication; information sharing; compassion and respect.

**3.1 Communication**

3.1.1 Poor communication and information sharing was a recurring theme across all five studies and related to hospital professionals who appeared to lack knowledge or awareness of the needs of people with intellectual disabilities and the importance of meeting their distinct needs (Howieson, 2015; Tuffrey-Wijne et al., 2014a; Tuffrey-Wijne et al., 2014b). Whilst it was acknowledged that professionals may not be able to spend prolonged time with adults with intellectual disabilities when admitted to the acute hospital setting, it was evident that for the person with intellectual disability this is an important care need and priority, *“I know they don’t have time, but they should make time, but they don’t do that”* (Howieson, 2015). There is the view amongst adults with intellectual disabilities that there is an avoidance of communication from healthcare professionals, perceived to be as a consequence of limited knowledge and understanding of their needs and the perceived additional workload associated with their care (Howieson, 2015; Tuffrey-Wijne et al., 2014a). This was further compounded by a perception that healthcare professionals prefer to speak directly to family members and carers rather than with the adult with intellectual disability with a desire that these staff *“facilitate service users to give their own account of their health status during clinical consultations”* (Walker et al., 2014).

3.1.2 Hospital passports: in two studies (Phillips, 2019; Tuffrey-Wijne et al., 2014b) the use of hospital passports and patient-held information documents containing essential personal information relating to an individual’s care and support needs, likes and dislikes, were perceived as a valuable tool to assist and inform the provision of person-centred care. The availability of health passports and patient-held information documents assisted in improving communication between adults with intellectual disabilities and healthcare professionals by ensuring that care needs and preferences were identified and addressed.

3.1.3 Intellectual disability liaison nurse:improvement in the communication and support being provided to adults with intellectual disabilities was valued when the ‘intellectual disability liaison nurse’ was introduced to general health care settings as these healthcare professionals possessed expert specialist knowledge, skills and understanding of the needs of those with intellectual disabilities (Phillips, 2019; Tuffrey-Wijne et al., 2014b; Walker et al., 2014). Adults with intellectual disabilities benefitted from being seen at a time and in a suitable place conducive to their needs as well as being supported by healthcare professionals who are familiar to them, *“she understood many of the issues that [my sister] had and was able to liaise”* (Tuffrey-Wijne et al., 2014b).

**3.2 Information sharing**

It was apparent across the studies that adults with intellectual disabilities wanted information to be shared to ensure suitable care and supports were provided in a way that met their individual needs (Howieson, 2015; Phillips, 2019; Tuffrey-Wijne et al., 2014b; Walker et al., 2014). Some adults with intellectual disabilities reported they would have benefitted more if their General Practitioner had informed the hospital that they had an intellectual disability at the time of referral, *“needs to be more communication between your doctor and the hospital”* (Howieson, 2015). Other adults with intellectual disabilities who had provided information, which included completion of a hospital passport, were able to benefit from reasonable adjustments, such as the use of pictorial supports, which were made to facilitate their journey throughout the hospital experience (Phillips, 2019; Walker et al., 2014). However, despite information being provided on particular needs, in some instances these were not always taken into account or utilised appropriately by healthcare professionals (Tuffrey-Wijne et al., 2014a; Walker et al., 2014). This apparent disregard contributed to delays in treatment and investigations, and inadequate or absent nursing care and support.

 Further, how information was presented to adults with intellectual disabilities sometimes fell short of their expectations (Howieson, 2015). Adults with intellectual disabilities called for healthcare professionals to use less ‘health jargon’ and simple language so that verbal information could be more fully communicated and understood, *“put it into words that I can understand”* (Howieson, 2015). In addition, the manner in which some conversations took place provoked feelings of discomfort and anxiety as the tone was not always friendly or appropriate, *“sometimes they can jump down your throat if you’ve got a learning disability”* (Howieson, 2015). Receipt of written information relating to a hospital attendance was problematic for some adults with intellectual disabilities as they found it difficult to read and understand due to an inaccessible format such as the absence of the use of pictures and larger fonts (Howieson, 2015; Phillips, 2019).

**3.3 Compassion and Respect**

A recurrent theme across the five studies was the need for healthcare staff to be cognisant of the need for adults with intellectual disabilities to have individualised support and adjustments to enable them to participate fully in their hospital experience (Howieson, 2015; Phillips, 2019; Tuffrey-Wijne et al., 2014a; Tuffrey-Wijne et al., 2014b; Walker et al., 2014).

Despite this, evidence emerged across multiple studies that adults with intellectual disabilities experienced feelings of being undervalued and treated without respect in their interactions with healthcare professionals (Howieson, 2015; Tuffrey-Wijne et al., 2014a; Tuffrey-Wijne et al., 2014b; Walker et al., 2014). Some adults with intellectual disabilities described not being listened to and being ignored by healthcare professionals resulting in them feeling ignored, anxious and vulnerable, *“doctors don’t listen to the things I’ve got to say”* (Howieson, 2015). This was further compounded when the need for pain relief was not being met and a family member had to intervene, *“I was in pain and needed medication. I had to get my mum to speak to them’*” (Tuffrey-Wijne et al., 2014a).

 The compassion and respect received by adults with intellectual disabilities by the intellectual disability liaison nurses was palpable as a result of these nurses having an understanding of individual needs and the ability to accommodate them in a way that was both individualised and person-centred (Phillips, 2019; Tuffrey-Wijne et al., 2014b). Adults with intellectual disabilities described this specialist support as a contributory factor in making their hospital visit a success and more enjoyable, *“the only time that went well is when I saw the intellectual disability liaison nurse”* (Tuffrey-Wijne et al., 2014b).

**4 DISCUSSION**

Whilst there are many studies presenting the experiences of healthcare professionals supporting adults with intellectual disabilities (Applegren et al., 2018; Drozd & Clinch, 2016; Lewis et al., 2017; Ndengeyingoma & Ruel, 2016), there are fewer studies presenting the experiences of adults with intellectual disabilities specifically.

 The findings of this review continue to highlight a need to address issues to enable a better experience for adults with intellectual disabilities when accessing acute hospital services, the style and approaches to communication, the attainment and provision of information and the need for compassion and respect. To protect adults with intellectual disabilities from discrimination and unfair and inequitable treatment, legislation and guidance is in place to ensure they are not treated less favourably than those who do not have a disability (Disability Discrimination Act,1995; Equality Act, 2010; GAIN, 2010; RQIA, 2018). However, this review and appraisal of the literature indicates that adults with intellectual disabilities acknowledge that while healthcare professionals do endeavour to respond to and accommodate their needs (MacArthur et al., 2015), there still exists significant shortcomings in compliance with legislation and policy and best practice guidance. This is particularly with regard to a lack of effective communication, respect and the implementation of reasonable adjustments (Tuffrey-Wijne et al., 2014b; Walker et al., 2014). These issues are detrimental to adults with intellectual disabilities in understanding and benefitting from the care, treatment and supports they require. However, adults with intellectual disabilities have also highlighted areas of good practice and positivity towards them, something which could be further developed and implemented (Castles et al., 2014; Heifetz & Lunsky, 2018; MacArthur et al., 2015; Phillips, 2019). The current findings are supportive of those set out in the systematic review undertaken by Iacono et al. (2014) and 16 studies in which the experiences of adults with intellectual disabilities using acute hospital services fell significantly short of their expectations. This continuing situation is one that requires a policy, practice and education focus to bring about sustainable long-term change that reduces the risk of harm and improves the care and support experiences and health outcomes for adults with intellectual disabilities.

 To ensure that support is provided to adults with intellectual disabilities, improving the awareness of their distinct care needs is essential. Recognising the importance of education and practice development is critical and adults with intellectual disabilities recognise that all healthcare professionals need to be fully aware of and respond to their specific needs to ensure that service developments and improvements occur, thereby providing a positive hospital experience with equality of care that improves health outcomes (Howieson, 2015). The hospital passport is a useful tool and contributes to better communication and understanding of specific care and support needs (Heifetz & Lunsky, 2018; Phillips, 2019; Tuffrey-Wijne et al., 2014b). However, although the hospital passport was prominent in literature in preceding years (Ali et al., 2013; Blair, 2011; Bradley et al., 2012; Dinsmore & Higgins, 2011; Wolfstadt et al., 2010), it was only specifically identified by Phillips (2019) and alluded to by Tuffrey-Wijne et al. (2014b) in the studies included in this review. There is therefore a need and an opportunity to undertake further research with adults with intellectual disabilities, their families, care and health professionals to more fully understand their impact in relation to the provision of safe and effective person-centred care and support and the improved health outcomes that they seek to achieve.

 Although adults with intellectual disabilities often attempt to inform healthcare professionals about their specific care and support needs, the communication approaches and implementation of reasonable adjustments is not always evident or consistent due to inadequate patient information systems, limited awareness and understanding of health professionals and accountability, and resources (Castles et al., 2014; Harris & Sheehan, 2017; Iacono et al., 2014; Tuffrey-Wijne et al., 2014b; Welyczko, 2018). This apparent indifference may also in part be due to a lack of specific disability awareness training and education (Tuffrey-Wijne et al., 2014a; Tuffrey-Wijne et al., 2014b). However, in the UK, reasonable adjustments are a fundamental right and protected by legislation (Disability Discrimination Act, 1995; Equality Act, 2010). Yet there is a dearth of information as to the extent of compliance within acute hospitals in the context of their duty under current legislation (Glover et al., 2016). Therefore, the apparent inconsistency in the delivery of accessible, person-centred services, care and support is an area requiring further research and practice development to identify legislation compliance and the associated impact and outcomes achieved (Tuffrey-Wijne et al., 2014b).

 In this review, adults with intellectual disabilities identified the role of the intellectual disability liaison nurse as important to a positive acute hospital experience. The role provided access to expert knowledge, skills and resources to identify and address any care and support issues to minimise the potential for harm and a poor care experience. The ability these nurses had to identify and implement reasonable adjustments improved the care experience of adults with intellectual disabilities, thereby enhancing their confidence and satisfaction (Castles et al., 2014; MacArthur et al., 2015). However, there is a further need to develop the scope and reach of the intellectual disability liaison nursing services to ensure provision is available out of ‘office hours’ (Castles et al., 2014; MacArthur et al., 2015). A future research focus is required to identify the extent to which adults with intellectual disabilities access acute hospital care outside ‘office hours’ and their care experiences and the health outcomes achieved.

 This systematic review has highlighted several areas requiring further service, education and research attention to address negative experiences and poor health outcomes, thereby aiming to develop and build on the positive experiences of adults with intellectual disabilities when accessing acute hospital services. A significant obstacle to positive hospital experiences for adults with intellectual disabilities has been the approach of healthcare professionals regarding communication and provision of information in an accessible format. Research suggests that registered nurses might feel underprepared and lack awareness, knowledge and skills when caring for patients with intellectual disabilities (Applegren, et al., 2018; Lewis et al., 2017). The ability to see the person before the disability and interpret nonverbal communication could enhance the relationship (Applegren, et al., 2018; Lewis et al., 2017). Research also indicates that targeted communication training for healthcare professionals to include listening to and sharing information with family caregivers could contribute to an improvement in the care of adults with intellectual disabilities (Charles, 2020). The feeling of being ignored and not being treated with respect is an issue that needs to be addressed with education and practice development required at both undergraduate and continuing professional development levels. Consequently, there is an opportunity to more fully understand the perspective of adults with intellectual disabilities and their families to start to more effectively target and direct the available resources to make the care experiences positive and improve health outcomes and reduce harm when accessing acute hospital services.

**4.1 Future research**

The studies included in this systematic review included a range of qualitative research methods which included focus groups, semi-structured interviews and a case study. There were no studies which reflected views and experiences internationally or in multicentred studies. No studies focused on factors that reduced harm by identifying how health outcomes could be improved and evidenced. Consequently, there is scope to undertake research studies to address these gaps, with an opportunity to include studies that are co-produced and conducted with adults with intellectual disabilities. Addressing these research gaps would evolve the evidence base of what works to improve the hospital experiences of adults with intellectual disabilities and the impact of the care and support provided by healthcare professionals. Further research focus is required regarding the extent to which the hospital passport is being used within acute hospitals and how well reasonable adjustments are being facilitated as a result and the impact on the provision of safe and effective care that improves health outcomes.

**4.2 Strengths and limitations**

A strength of the current review is the identification and analysis of studies focusing exclusively on the views and experiences of adults with intellectual disabilities when accessing acute hospitals. An evidence-based approach was used for the literature search and extraction, and a structured approach was used for evaluating quality in the literature. However, the number of included articles was less than anticipated. Two potential contributors to this were the narrow scope of terms used and the restrictive inclusion criteria for studies. It is recognised that including broader search terms for example ‘developmental disabilit\*’ and ‘acute care’ may have generated additional papers. This review has identified that despite legislation and ongoing initiatives to improve the care and support of adults with intellectual disabilities when accessing acute hospitals, there remains an apparent absence of individualised support and compassionate care, specific to the needs of this population. There is the possibility of bias in study selection and quality appraisal despite two authors reviewing the selection and results. Furthermore, while the authors sought to be robust in the search for relevant studies, it is acknowledged that some studies might have been overlooked and this is therefore a potential limitation.

**5 CONCLUSION**

Despite legislation mandating equality and protection, this systematic review reveals the need for further improvements to the provision of care for people with intellectual disabilities who access acute hospital services. These include the need to improve communication between hospital staff and patients with intellectual disabilities, to enhance communication sharing, and to ensure staff show a greater level of compassion and respect towards adults with intellectual disabilities. An inconsistent approach in the identification and implementation of reasonable adjustments and the provision of information in accessible formats is an area that requires further development and attention. From the perspectives of adults with intellectual disabilities it is evident that there are attempts being made to address their concerns and needs in some acute hospitals, but more consistent, sustained development and action needs to be taken. This review highlights the benefits of the intellectual disability liaison nurse, with the need for the hospital passport to be consistently utilised by all healthcare professionals and embedded in acute hospital processes. In addition, considering the positive impact of the intellectual disability liaison nursing service the provision of extended hours would be a much-valued resource contributing to an increase in the positive experiences of people with intellectual disabilities when accessing acute hospital services.

 Adults with intellectual disabilities have a legal and moral right to receive care and support in acute hospitals that is respectful, safe and person-centred, thereby positively impacting on their healthcare experience and health outcomes. For this to be a reality, there is a need to ensure healthcare professionals are supported to develop and obtain the necessary knowledge and skills to ensure they become routinised within everyday practice in all acute hospital settings, thereby improving the experiences of adults with intellectual disabilities when accessing acute hospital services.

**REFERENCES**

Ali, A., Scior, K., Ratti, V., Strydom, A., King, M. & Hassiotis, A. (2013). Discrimination and Other Barriers to Accessing Health Care: Perspectives of Patients with Mild and Moderate Intellectual Disability and Their Carers. *PLoS ONE* 8(8), Article e70855. https://doi.org/10.1371/journal.pone.0070855.

Applegren M., Bahtsevani C., Persson K. & Borglin G. (2018). Nurses’ experiences of caring for patients with intellectual developmental disorders: a systematic review using a meta-ethnographic approach. *BMC Nursing*, 17-51. https://doi.org/10.1186/s12912-018-0316-9.

Backer C., Chapman M. & Mitchell D. (2009). Access to secondary healthcare for people with intellectual disabilities: a review of the literature. *Journal of Applied Research in Intellectual Disabilities* 22, 514–525.

Bell R. (2012). Does he have sugar in his tea? Communication between people with learning disabilities, their carers and hospital staff. *Tizard Learning Disability Review* 17(2), 57-63.

Bittles A.H., Petterson, B.A., Sullivan, S.G., Hussain, R., Glasson, E.J. & Montgomery, P.D. (2002). The Influence of Intellectual Disability on Life Expectancy, *Journal of Gerontology* 57(7), 470-472.

Blair J. (2011). Care adjustments for people with learning disabilities in hospitals. *Nursing Management* 28(8), 21-24.

Braddock, D., Emerson, E., Felce, D. & Stancliffe, R.J. (2001). Living circumstances of children and adults with mental retardation or developmental disabilities in the United States, Canada, England and Wales, and Australia. *Mental Retardation and Developmental Disabilities Research Reviews* 7(2), 115-121.

Bradley, P., Byrne, K. & Ring, H.A. (2012). How to get the most from a consultation with a person who has a learning disability. *Practical Neurology* 12, 44-48*.*

Caldwell K., Henshaw I. & Taylor G. (2011). Developing a framework for critiquing health research: An early evaluation. *Nurse Education Today* 31(8), 1-7.

Care Quality Commission (2012). Learning disability services inspection programme: National overview, Newcastle upon Tyne, Care Quality Commission. Retrieved from www.cqc.org.uk/sites/default/files/documents/cqc\_ld\_review\_national\_overview.pdf

Castles, A., Bailey, C., Gates, B. & Sooben, R. (2014). Experiences of the implementation of a learning disability nursing liaison service within an acute hospital setting: a service evaluation. *British Journal of Learning Disabilities* 42(4), 272-281.

Charles, M.L. (2020). Communication experiences of family caregivers of hospitalized adults with intellectual and developmental disabilities – A qualitative study. *Nursing Open*. 2020;00:1-10. https://doi.org/10.1002/nop2.557.

Critical Appraisal Skills Programme (2013). *Ten questions to help you make sense of qualitative research*. Oxford, Critical Appraisal Skills Programme.

Dinsmore, A.P. (2011). A small-scale investigation of hospital experiences among people with a learning disability on Merseyside: speaking with patients and their carers. *British Journal of Learning Disabilities* 40, 201-212.

 https://doi.org/10.1111/j.1468-3156.2011.00694.x.

Dinsmore, A. & Higgins, L. (2011). Study of patients’ experiences of treatment by hospital staff. *Learning Disability Practice* 14(5), 18-22.

Disability Discrimination Act (1995). Retrieved from www.legislation.gov.uk/ukpga/1995/50/data.pdf

Drozd, M. & Clinch, C. (2016). The experiences of orthopaedic and trauma nurses who have cared for adults with a learning disability. *International Journal of Orthopaedic and Trauma Nursing*. https://doi.org/10.1016/j.ijotn.2015.08.003.

Drozd, M., Chadwick, D., Jester, R. (2020). An integrative review of the hospital experiences of people with an intellectual disability: Lack of orthopaedic and trauma perspectives. *International Journal of Orthopaedic and Trauma Nursing.* https://doi.org/10.1016/j.ijotn.2020.100795

Emerson E. & Heslop P. (2010). A Working Definition of Learning Disabilities. Improving Health and Lives: Learning Disabilities Observatory, Lancaster/London.

Equality Act (2010). Her Majesty’s Stationery Office and Queen’s Printer of Acts of Parliament. Retrieved from www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga\_20100015\_en.pdf

Glover, G., Fox, S. & Hatton, C. (2016). General hospital care for people with intellectual disabilities. *Tizard Learning Disability Review* 21(1), 44-49.

Guidelines and Audit Implementation Network (2010). Guidelines on Caring for People with a Learning Disability in General Hospital Settings. Retrieved from https://rqia.org.uk/RQIA/files/81/81662c46-b7bb-43a5-9496-a7f2d919c2a3.pdf

Harris, L. & Sheehan, R. (2017). Hospital care for people with learning disability. *British Journal of Hospital Medicine* 78(10), C156-C160.

Heifetz, M. & Lunsky, Y. (2018). Implementation and evaluation of health passport communication tools in emergency departments. *Research in Developmental Disabilities* 72, 23-32.

Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A. & Russ, L. (2013a). Confidential inquiry into the premature deaths of people with learning disabilities. Bristol, Norah Fry Research Centre. Retrieved from www.bristol.ac.uk/medialibrary/sites/cipold/migrated/documents/fullfinalreport.pdf

Heslop, P., Hoghton, M., Blair, P., Fleming, P., Marriott, A., & Russ, L. (2013b). The need for FASTER CARE in the diagnosis of illness in people with intellectual disabilities. *British Journal of General Practice* 63(617), 661-662.

Howieson, J. (2015). Experiences of acute hospital services among people with mild to moderate learning disabilities. *Learning Disability Practice* 18(9), 34-38.

Iacono, T., Bigby, C., Unsworth, C., Douglas, J. & Fitzpatrick, P. (2014). A systematic review of hospital experiences of people with intellectual disability. *BMC Health Services Research* 14(505). http://www.biomedcentral.com/1472-6963/14/505.

Learning Disabilities Mortality Review (LeDeR) Programme (2018). Annual Report, Bristol, Norah Fry Research Centre. Retrieved from http://www.bristol.ac.uk/medialibrary/sites/sps/leder/LeDeR\_Annual\_Report\_2018%2 0published%20May%202019.pdf

Lewis P., Gaffney, R.J. & Wilson, N.J. (2017). A narrative review of acute care nurses’ experiences nursing patients with intellectual disability: underprepared, communication barriers and ambiguity about the role of caregivers. *Journal of Clinical Nursing* 26, 1473–1484.

MacArthur, J., Brown, M., McKechanie, A., Mack, S., Hayes, M. & Fletcher, J. (2015). Making reasonable and achievable adjustments: the contributions of learning disability liaison nurses in 'Getting it right' for people with learning disabilities receiving general hospitals care. *Journal of Advanced Nursing* 71(7), 1552-1563.

Mencap (2007). Death by Indifference: Following up the *Treat me right!* report. London, Mencap. Retrieved from https://www.mencap.org.uk/sites/default/files/201606/DBIreport.pdf

Mencap (2012). Death by *indifference*: 74 deaths and counting: A progress report 5 years on, London, Mencap. Retrieved from www.mencap.org.uk/sites/default/files/201608/Death%20by%20Indifference%20%20 74%20deaths%20and%20counting.pdf

Michael J. (2008). *Healthcare for All: Report of the Independent Inquiry Into Access to*  *Healthcare for People with Learning Disabilities.* London, Department of Health.

Moher D., Shamseer L. & Clarke M. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews* 4(1), 1–9.

Nagarajappa, R., Tak, M., Sharda, A., Asawa, K., Jalihal, S. & Kakatkar, G. (2013). Dentists’ attitude to provision of care for people with learning disabilities in Udaipur, India. *Scandinavian Journal of Caring Sciences* 27(1), 57-62.

Ndengeyingoma, A. & Ruel, J. (2016). Nurses' representations of caring for intellectually disabled patients and perceived needs to ensure quality care. *Journal of Clinical Nursing* 25, 21-22, 3199-3208.

Perusini, A.J., Llacuachaqui, M., Sigal, M.J. & Dempster, L.J. (2016). Dental Students’ Clinical Expectations and Experiences Treating Persons with Disabilities. *Journal of Dental Education* 80(3), 301-310.

Phillips, L. (2019). Learning disabilities: making reasonable adjustments in hospital. *Nursing Times* 115(10), 38-42.

Public Health England (2016). People with learning disabilities in England 2015: Main report. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attach ment\_data/file/613182/PWLDIE\_2015\_main\_report\_NB090517.pdf

Regulatory Quality Inspection Authority (2016). Review of Adult Learning Disability Community Services Phase II. Retrieved from https://www.rqia.org.uk/RQIA/files/4a/4a883fbc-92a7-4fda-97b0-ac2e664e5d8d.pdf

Regulation and Quality Improvement Authority (2018). Guidelines on Caring for People with a Learning Disability in General Hospital Settings. Retrieved from https://rqia.org.uk/RQIA/files/41/41a812c6-fee8-45ba-81b8-9ed4106cf49a.pdf

Rushbrooke, E., Murray, C.D. & Townsend, S. (2014). What difficulties are experienced by caregivers in relation to the sexuality of people with intellectual disabilities? A qualitative meta-synthesis. *Research in Developmental Disabilities*, 35(4), 871-886.

Shield, J., Turner, L., Pierce, S. & Wheatcroft, D. (2013). Dental Services for People with Learning Disabilities. *Learning Disability Practice* 16(1), 12-15.

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

Tuffrey-Wijne, I., Goulding, L., Giatras, N., Abraham, E., Gillard, S., White, S., Edwards, C. & Hollins, S. (2014b). The barriers to and enablers of providing reasonably adjusted health services to patients with learning disabilities in acute hospitals: evidence from a mixed-methods study. *BMJ Open* 4, Article e004606. http://dx.doi.org/10.1136/bmjopen-2013-004606.

Walker, C., Beck, C.R., Eccles, R. & Weston, C. (2014). Health inequalities and access to health care for adults with learning disabilities in Lincolnshire. *British Journal of Learning Disabilities* 44(1), 16-23.

Welyczko, N. (2018). Working with patients with long-term conditions and learning disabilities. *Journal of Kidney Care* 3(4), 224-228.

Wolfstadt, J., Kaufman, B.A., Levitin, J. & Kaufman, M. (2010). The use and usefulness of My Health passport: An online tool for the creation of a portable health summary. *International Journal of Child and Adolescent Health* 3(4), 499-506.

World Health Organisation (2016). The Global strategy and action plan on ageing and health. Retrieved from https://www.who.int/ageing/global-strategy/en/

 World Health Organisation (2018). Disability and Health. Geneva, World Health Organisation.

Williamson, H. & Meddings, S. (2018). Exploring family members’ experiences of the Assessment and Treatment Unit supporting their relative. *British Journal of Learning Disabilities* 46(4), 233-240. https://doi.org/10.1111/bld.12234.

**TABLE 1** PsycINFO search strategy and results

|  |  |  |
| --- | --- | --- |
| **Search code** | **Query** | **Results** |
| 1 | intellectual disability | 23529 |
| 2 | learning disabilit\* | 26564 |
| 3 | 1 or 2 | 49141 |
| 4 | hospital\* | 186049 |
| 5 | 3 and 4 | 2024 |
| 6 | experience | 395481 |
| 7 | 5 and 6 | 165 |
| 8 | limit 7 to (english language and yr=“2014-2020”) | 41 |

\* denotes variations of the term e.g. hospital, hospitals

**TABLE 2** Papers included in the review (n=5)

| **Study Citation and Country** | **Aims** | **Sample** | **Study Setting** | **Data collection method** | **Key Findings** | **Recommendations** |
| --- | --- | --- | --- | --- | --- | --- |
| Howieson, J.(2015)UK | Experiences of adults with intellectual disabilities in acute hospital services.  | Adults with intellectual disabilities (n=7) | Acute hospital services (Scotland) | Focus groups (n=2) | Adults with intellectual disabilities felt disrespectedand undervalued when staff communicated with them in a less than helpful manner. Adults with intellectual disabilities would prefer more information on their intellectual disability and requirements to be provided to hospitals by their GPs.  | Adults with intellectual disabilities want staff to spend time with them and be more supportive. Adults with intellectual disabilities want to feel valued and treated with dignity in terms of how information is delivered to them and attitudes of staff towards them. |
| Phillips, L.(2019)UK | Exploration of reasonable adjustments in hospital. | Adult with an intellectual disability (n=1) | Surgical ward in an acute hospital(Wales) | Case study | The use of the hospital passport and implementation of reasonable adjustments improved the hospital experience.  | Healthcare staff should engage with people with intellectual disabilities to identify and implement reasonable adjustments. |
| Tuffrey-Wijne et al.(2014a)UK | The experiences of adults with intellectual disabilities in relation to safety incidents in acute hospitals. | Adults with intellectual disabilities (aged 16 or over) (n=33) | NHS acute hospital trusts in England (n=6) | Semi-structured interviews  | Healthcare staff often overlooked and avoided the care of adults with intellectual disabilities resulting in lack of monitoring of general wellbeing and treatment of pain.  | Adults with intellectual disabilities want to be treated with respect. Training for healthcare staff on communication and disability awareness is critical.  |
| Tuffrey-Wijne et al.(2014b)UK | The experiences of adults with intellectual disabilities receiving reasonable adjustments in acute hospitals. | Adults with intellectual disabilities (aged 16 or over) (n=33) | NHS acute hospital trusts in England (n=6) | Semi-structured interviews | Adults with intellectual disabilities benefitted from reasonable adjustments tailored to their needs. Communication was poor except where the support of a learning disability liaison nurse was available.  | Adults with intellectual disabilities want to be kept up to date and valued.  |
| Walker, et al.(2014)UK | To compare the health of adults with intellectual disabilities to the rest of the population.  | Adults with intellectual disabilities (n=30)aged 18-60  | Outpatient treatment and inpatient stays in NHS Lincolnshire | Small discussion groups (n=5) | Adults with intellectual disabilities felt they were not kept informed or adequately supported and information they provide is not always taken into consideration therefore they consider a support person is vital.  | Adults with intellectual disabilities want healthcare staff to give greater support to facilitate them to give their own account of their health status.  |

**TABLE 3** CASP Quality Scores (n=5)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **CASP criteria** | Howieson(2015) | Phillips(2019) | Tuffrey-Wijne et al. (2014a) | Tuffrey-Wijne et al. (2014b) | Walkeret al.(2014) |
| 1 Clear statement of aims | 1 | 2 | 2 | 2 | 2 |
| 2 Appropriate methodology | 1 | 2 | 2 | 2 | 2 |
| 3 Appropriateresearch design | 1 | 2 | 2 | 2 | 1 |
| 4 Appropriate recruitment strategy | 1 | 0 | 2 | 2 | 1 |
| 5 Appropriate data collection methods | 1 | 1 | 2 | 2 | 1 |
| 6 Researchrelationships considered | 0 | 1 | 2 | 2 | 0 |
| 7 Consider ethical issues | 2 | 0 | 2 | 2 | 0 |
| 8 Rigorous analysis | 1 | 0 | 2 | 2 | 1 |
| 9 Clear findings | 1 | 1 | 2 | 2 | 1 |
| 10 Value of the research | 1 | 1 | 2 | 2 | 1 |
| Total scores out of 20 | 10 | 10 | 20 | 20 | 10 |

2 = explicit 1 = partially explicit 0 = not mentioned

**FIGURE 1** PRISMA flow diagram with search results