The 4C framework for making reasonable adjustments for people with learning disabilities

Abstract

Background

People with learning disabilities experience significant inequalities in accessing healthcare. Legal frameworks, such as the Equality Act 2010, are intended to reduce such disparities in care, and require organisations to make 'reasonable adjustments' for people with disabilities, including learning disabilities. However, reasonable adjustments are often not clearly defined or adequately implemented in clinical practice.

Aim

To examine and synthesise the challenges in caring for people with learning disabilities to develop a framework for making reasonable adjustments for people with learning disabilities in hospital. This framework would assist ward staff in identifying and managing the challenges of delivering person-centred, safe and effective healthcare to people with learning disabilities in this setting.

Method

Fourth-generation evaluation, collaborative thematic analysis, reflection and a secondary analysis were used to develop a framework for making reasonable adjustments in the hospital setting. The authors attended ward manager and matron group meetings to collect their claims, concerns and issues, then conducted a collaborative thematic analysis with the group members to identify the main themes.

Findings

Four main themes were identified from the ward manager and matron group meetings: communication, choice-making, collaboration and coordination. These were used to develop the 4C framework for making reasonable adjustments for people with learning disabilities in hospital.

Discussion

The 4C framework has provided a basis for delivering person-centred care for people with learning disabilities. It has been used to inform training needs analyses, develop audit tools to review delivery of care that is adjusted appropriately to the individual patient; and to develop competencies for learning disability champions. The most significant benefit of the 4C framework has been in helping to evaluate and resolve practice-based scenarios.

Conclusion

Use of the 4C framework may enhance the care of people with learning disabilities in hospital, by enabling reasonable adjustments to be made in these settings.

EVIDENCE FOCUSING ON how people with learning disabilities, their families and care workers experience care in the NHS has prompted healthcare providers to examine the services delivered and the deficiencies inherent in healthcare systems (Disability Rights Commission (DRC) 2006, Mencap 2007, Michael 2008, Parliamentary and Health Service Ombudsman 2009, Mencap 2012, Heslop et al 2013).

The NHS Plan: A Plan for Investment, A Plan for Reform (Department of Health (DH) 2000) offered nurses opportunities to develop and expand their roles. Valuing People: A New Strategy for Learning Disability for the 21st Century (DH 2001) and Action for Health, Health Action Plans and Health Facilitation: Detailed Good Practice Guidance on Implementation for Learning Disability Partnership Boards (DH 2003) capitalised on this, using evidence from professional networks (Cumella and Martin 2000) to identify a health facilitation role, which became a model for the hospital learning disability liaison roles developed by commissioners. There is evidence for the influence, value and effectiveness that these posts can have in facilitating care for people with learning disabilities and in ensuring the requirements of the Equality Act 2010 are met (MacArthur et al 2010, Tuffrey-Wijne et al 2014).

The Disability Discrimination Act 1995 and the Equality Act 2010 sought to protect people with disabilities in law, requiring all public bodies to make 'reasonable adjustments' to their premises, policies and services for people with disabilities. There has been guidance on reasonable adjustments in practice and examples of reasonable adjustments have been provided (Giraud-Saunders 2009). However, a framework has not been provided for ward staff working in hospitals.

Background

The government prioritised the health of people with learning disabilities in Valuing People: A New Strategy for Learning Disability for the 21st Century (DH 2001). Death by Indifference: Following up the Treat Me Right! Report (Mencap 2007) identified delays in diagnosis and issues with the treatment of people with learning disabilities, resulting from failures to implement legal frameworks relating to the Mental Capacity Act 2005 and the Disability Discrimination Act 1995.

Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities (Michael 2008) made recommendations for healthcare providers on how to improve access to healthcare for people with learning disabilities. Monitor, the health services regulator in England, requests quarterly self-assessment of compliance with these recommendations (Monitor 2015). At a national level, the Improving Health and Lives Learning Disabilities Observatory was established as part of Public Health England to monitor and report on the extent and nature of health inequalities for people with learning disabilities and the role of NHS services (Walker et al 2014).

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (Heslop et al 2013) identified that women with learning disabilities died an average of 20 years earlier than women in the general UK population, while men with learning disabilities died an average of 13 years earlier than men in the general UK population. All cause-specific mortality rates of people with learning disabilities in the UK are three times higher than in the general population (Emerson and Bains 2010), and there were almost double the number of avoidable deaths in people with learning disabilities in England (18.8%) as in the general population (10.4%) in 2010 (Emerson et al 2012).

More recently, the Independent Review of Deaths of People with a Learning Disability or Mental Health Problem in Contact with Southern Health NHS Foundation Trust April 2011 to March 2015 – the Mazars report investigating the deaths of people with learning disabilities (Green et al 2015) – found discrepancies in reporting and in investigations of unexpected deaths, which, along with the NHS England commissioned Learning Disability Mortality Review Programme (Health Quality Improvement Partnership (HQIP) 2015), are likely to have a significant effect during 2017, since all

deaths of people with learning disabilities will be reviewed with some multiagency investigation (HQIP 2015).

Learning disability nurse consultants undertook a review of the evidence for health inequalities for people with learning disabilities, to develop a health equalities framework with improved outcome measures (Atkinson et al 2014). Five main factors were identified that cause disparities in health outcomes for people with learning disabilities (Atkinson et al 2014):

» Social determinants of health.

» Genetic and biological factors.

» Communication and health literacy.

» Behaviour and lifestyle issues.

» The quality of local services.

The Equality Act and person-centred care

The Equality Act 2010 sought to rationalise and simplify previous anti-discriminatory law. The Disability Discrimination Act 1995 placed a duty on all public bodies to make 'reasonable adjustments' to their premises, policies and services. This duty became a requirement under the Equality Act 2010, which enshrines in law the rights of people with disabilities to have equal access to all public services. The Equality Act 2010 specifies two types of reasonable adjustments that enable equal access for people with disabilities: individual adjustments, based on the disadvantage to the individual, and a duty for service providers to make anticipatory adjustments, based on the needs of a group of people with particular disabilities.

Individual adjustments tend to be reactive, whereas actions to anticipate what might be required seek to ensure equality of access in advance. In law, people with learning disabilities would be considered to be a group who are disadvantaged in accessing healthcare (The Equality Act 2010); therefore, healthcare providers have a legal duty to make anticipatory adjustments to ensure access to the service is as close as possible to that experienced by others. It would appear advantageous to expect anticipatory adjustments to be planned for, from a legal perspective. However, it is acknowledged that people with learning disabilities are not a homogenous group. The duty to make anticipatory adjustments could encourage the courts to prioritise general adjustments above the ad hoc adjustments required to meet an individual's needs (Tyrer 2015).

Manley et al (2011) considered equality and human rights as central to person-centred care. The European Convention on Human Rights is supported in the UK by various laws, including the Human Rights Act 1998, the Mental Capacity Act 2005 and the Equality Act 2010. People with disabilities are able to claim they have a legal right to person-centred care by way of reasonable adjustments. Legal requirements have had less success in initiating the culture change required to enable the provision of mainstream healthcare services based on an individual's holistic requirements. Many healthcare organisations have endeavoured to define how reasonable adjustments might appear (DH 2009, Turner and Robinson 2011, Royal College of Nursing (RCN) 2013). However, there is an absence of strategies and practical suggestions to enable these adjustments to be made in these settings.

Aim

The aim of this study was to examine and synthesise the challenges in caring for people with learning disabilities

to develop a framework for making reasonable adjustments for people with learning disabilities in hospital. This framework would assist ward staff in identifying and managing the challenges of delivering person-centred, safe and effective healthcare to people with learning disabilities in this setting.

Method

Practice development is an approach to sustainable practice change, with the intention of achieving person-centred workplace cultures, which enables healthcare professionals and multidisciplinary teams to provide services based on each individual's needs (Manley et al 2008). Robust practice development methods that contribute to engendering a culture of effectiveness were used to develop the 4C framework for making reasonable adjustments for people with learning disabilities. These methods acknowledge that often the best learning resource and environment for healthcare professionals is the workplace. Manley et al (2014) indicated that practice development was central to developing a shared purpose and values, in contrast to top-down, cascading methods.

An adapted liaison model was used to develop the 4C framework in 2012. A practice development nurse for people with learning disabilities (DM) provided clinical and strategic leadership to approximately 7,000 staff in three acute hospitals. Use of this model prompted inquiry into which activities would have the greatest influence in supporting hospital staff to deliver person-centred, safe and effective care for people with learning disabilities.

A fourth-generation evaluation approach was selected (Guba and Lincoln 1989), which supports groups to establish the nature of their social reality through debate and discussion, rather than evaluating it by measurement, description or judgement (Carney 1991). A three-stage methodology was used. The first stage of the evaluation involved collecting healthcare professionals' claims, concerns and issues during three ward manager and matron group meetings in the hospitals.

First stage: claims, concerns and issues

Fourth generation evaluation uses claims, concerns and issues as prompts to solicit participants' initial contributions, in this case in relation to working with and caring for people with learning disabilities in hospital. This information was collected during visits to three ward manager and matron meetings in each of the three hospitals in the NHS trust, involving 68 ward managers and matrons. These were regular meetings that occurred weekly.

This activity created rich debate and instantaneous problem-solving. For example, when one ward manager identified that having a family carer staying overnight would be useful but that they felt unhappy about asking them to stay on hard-backed chairs, another nurse advised them that there were beds and rooms available for families in extenuating circumstances.

Second stage: thematic analysis

The second stage involved ward manager and matron meetings to undertake a collective thematic analysis, in each of the three groups. Two months after the initial visits, further visits were arranged to the three ward manager and matron meetings. The results of the meetings from the first stage were printed out and cut into strips of paper, to enable people in each of the three meetings to perform a collaborative thematic analysis of the evidence (Dixon-Wood et al 2008). This method of conducting a thematic analysis enables groups of people to engage in the interpretation and meanings of the words in a way that would not occur in a general discussion or training session.

The three ward manager and matron meetings undertook this analysis in different ways. Those attending one meeting worked together and discussed the definitions and debated the themes, while people in the second elected a leader to undertake this task on behalf of the meeting, after which they all commented on the results. Those in the third meeting were initially resistant to undertaking this activity, asking why the facilitator had not completed the task themselves, but did then undertake the activity.

The Promoting Action on Research in Health Services framework (Rycroft-Malone 2013) provided a useful method of interpreting this activity. The facilitator (DM) supported ward managers and matrons to reflect on the workplace context and evidence base during the meetings. They contributed by identifying adjustments that could be made and collaborating in the formation of the 4C framework for making reasonable adjustments for people with learning disabilities in hospital.

Third stage: secondary thematic analysis

The final stage involved a secondary analysis of the data that had been collected in the ward manager and matron meetings, involving a group of ward nursing staff and people with learning disabilities. This information was collated in an electronic file and shared via email with all who attended the meetings, including those people with learning disabilities. Once the thematic analyses had been gathered from the three ward manager and matron meetings, these analyses were shared with all the participants. A multi-partner group was formed to conduct a secondary thematic analysis, comprising people with learning disabilities, learning disability nurses and hospital staff, members of each of the three ward manager and matron meetings and the authors.

Findings

The secondary thematic analysis identified four themes that were important for making reasonable adjustments and improving care delivery for people with learning disabilities. These were:

» Communication.

» Choice-making.

» Collaboration.

» Coordination.

Each of these themes prompt changes to usual practice, within the limitations of the resources available. Therefore, the multi-partner group identified these four themes as a framework for making reasonable adjustments under the Equality Act 2010, known as the ‘4C framework’.

The 4C framework for making reasonable adjustments for people with learning disabilities in hospital provides a context for healthcare professionals on the ward to provide care and support to people with learning disabilities. It also provides a basis for wider practice and service development activities for other groups of potentially vulnerable patients in acute hospital care. The four themes of the 4C framework should be considered sequentially by healthcare professionals to enable them to pose questions and gather information on how the individual’s care can best be delivered.

Communication

McCormack and McCance (2010) emphasised that person-centred outcomes are based on the person’s involvement in their care. Evidence suggests that 90% of people with learning disabilities in the UK may have a communication impairment

(Bhaumik et al 2008). Therefore, hospital staff should consider what adjustments they may be required to make to their communication style, techniques and abilities.

There are various tools and services available to enable these adjustments to be made. These include The Hospital Communication Book (Clear Communication People 2014) and My Healthcare Passport for individualised information (East Kent Hospitals University NHS Foundation Trust 2012). These can also be used to communicate with other potentially vulnerable patients and patient groups. Interpreting services are also important, and technological advances make it possible for British Sign Language (BSL) and Makaton signing interpreters to be available via tablet computers. Questions relating to how the patient expresses pain are particularly significant.

Choice-making

Choice-making in healthcare is essential in engaging individuals in processes and procedures that can be painful and emotionally distressing. The Mental Capacity Act 2005 states that a person must be assumed to have capacity unless it is established that they lack capacity. The two-stage test should be used to assess a person's capacity to make a decision, based on if they have 'an impairment of, or a disturbance in the functioning of, the mind or brain' (Department for Constitutional Affairs 2007), and if this impairment or disturbance affects their ability to make informed choices for significant decisions. In hospital, this is usually interpreted to mean that procedures require a consent process.

In acute care it is often assumed that doctors will undertake most capacity assessments, based on their role proposing serious medical treatments. However, the wide, varied and ever-expanding roles of nurses and other healthcare professionals mean that a working knowledge of the law is essential to ensure proposed significant invasive procedures are completed appropriately and effectively. Effective working knowledge of the Mental Capacity Act 2005, the healthcare practitioners' role, the role of other partners in care, and the effect these have on care pathways and service delivery is essential to avoid delays in delivering care. Capacity is often paired with consent, but this does not necessarily mean that only those involved in formal consent processes should be experts in capacity. Everyone has a role in assessing capacity and identifying that the individual might have difficulties understanding, retaining, weighing up and expressing a choice about an issue as early as possible.

Following the Cheshire West and Chester Council v P [2014] case, in regard to whether living arrangements for a mentally incapacitated person amount to deprivation of liberty, practitioners should consider the following questions: 1. Is the person subject to continuous supervision and control?

2. Is the person free to leave?

These questions present challenging ethical, legal and practical dilemmas for hospital staff caring for people who might lack capacity. However, any concerns about these questions should result in completion of a Deprivation of Liberty Safeguards checklist, with an application for urgent authorisation of deprivation of liberty being made as required (Department for Constitutional Affairs 2007). Mencap (2007, 2012) noted in their Death by Indifference reports that there were delays in diagnosis and treatment, in part as a result of a lack of understanding of the Mental Capacity Act 2005. Significant advances have been made in enabling people with learning disabilities to exercise their rights under the law, in line with Article 12 of the Convention on the Rights of Persons with Disabilities

(United Nations 2006), giving people with disabilities equal recognition before the law. However, further work is required to ensure healthcare practitioners are able to safeguard people at risk.

The 4C framework for making reasonable adjustments draws attention to the issue of capacity. Tools and guidance are available (www.ekhuft.nhs.uk/learningdisabilities) to support healthcare professionals with assessment and adaptation of their care pathways to anticipate and accommodate this group of patients.

Collaboration

In the context of the 4C framework, collaboration means working together and engaging with others to contribute to the care of people with learning disabilities. The first issue to consider is who the appointed 'decision-maker' (Department for Constitutional Affairs 2007) should consult if the patient lacks capacity to make decisions about their current or forthcoming care and medical treatments. The Mental Capacity Act 2005 indicates that if the person does not have a next of kin, referred to as being unbefriended', the decision-maker has a responsibility to involve an independent mental capacity advocate.

It is not unusual for there to be many partners in the care provision for people with learning disabilities. These may include family members, social care workers and community healthcare professionals, such as care managers, speech therapists, physiotherapists, occupational therapists and community nurses. They all have a significant role in supporting the individual and will have vital information about them. Community healthcare professionals may not be aware that the individual has been admitted to hospital; therefore, it is important for them to know how to access the expertise of the community learning disability teams. Local safeguarding teams are also an important source of knowledge and resources for problem-solving in line with legal frameworks.

Coordination

The Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry (Francis 2013) identified that care in hospital required better coordination, observing that the 'named nurse' system, or something similar, was essential to enable healthcare professionals to have detailed knowledge of the medical, nursing and ancillary care organised and planned for the individuals they care for. The named nurse should provide up-to-date information to patients and carers, and who the ward manager can rely on to organise care.

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (Heslop et al 2013) observed that a major cause of premature deaths was a lack of coordinated care in care pathways and recommended that

a named healthcare coordinator should be appointed for people with complex or multiple health needs or two or more long-term conditions. Both reports acknowledged the effects that a lack of coordinated care can have on potentially vulnerable people in hospital. Therefore, it is essential to coordinate care at every level. This might involve bedside handovers, using tools such as those in the East Kent Hospitals University NHS Foundation Trust (www.ekhuft. nhs.uk/EasySiteWeb/GatewayLink. aspx?alId=426069) to negotiate roles with care workers, arranging effective lines of communication with care home managers or linking up with the commissioning care manager – to ensure planning for discharge is on course and that the right support and equipment will be available – or community learning disabilities nurse, using documentation to record joint plans of care together.

As Francis (2013) observed, this coordination role is best managed by ward-based nurses. This role involves significant leadership, which experienced nurses are better able to manage. However, creative problem-solving and anticipatory adjustment-making can be enabled throughout the organisation, through ducation, training and the appointment of learning disability champions.

Discussion

The 4C framework has provided a basis for delivering person-centred care (Manley et al 2014) for people with learning disabilities since its development in 2012. It has also provided structure to the organisation's learning disability pages at www.ekhuft. nhs.uk/learningdisabilities, where resources for each of the four themes are available. The 4C framework has been used to inform training needs analyses, develop audit tools to review delivery of care that is adjusted appropriately to the individual patient; and to develop competencies for learning disability champions.

Use of the 4C framework is best exemplified using a case study from clinical practice (Box 1). James's case is an example of what is possible when systems re in place to ensure that people with learning disabilities receive a service that is person-centred. Simple adjustments to communication techniques enabled James to experience a service working with him, rather than 'on' him. They enabled him to be given time to reflect on his healthcare choices.

Case Study

James was a 56-year-old man with cerebral palsy who lived in a large residential home with 15 other people with learning disabilities. On his first admission to hospital in several years, James was admitted via the emergency department to the clinical decision unit, following a period of vomiting and weight loss. James was flagged as having a learning disability on the patient administration system's special register. The practice development nurse for people with learning disabilities was alerted to his admission by an app for Apple devices that used this information.

The practice development nurse for people with learning disabilities visited James and reviewed his care until this point against the 4C framework for making reasonable adjustments. The practice development nurse and ward staff sourced a copy of The Hospital Communication Book (Clear Communication People 2014) and My Healthcare Passport (East Kent Hospitals University NHS Foundation Trust 2012), a tool developed with and by people with learning disabilities in East Kent to enable ward staff to understand those who might not be able to give a full verbal history.

The Hospital Communication Book was a vital tool for James and enabled an effective working and caring relationship to develop between James and the ward staff. He was able to manipulate the book and turn the pages to get his message across, which reassured care workers that James would not be dependent on them to interpret communication. James was discharged home after being reviewed and observed.

Two weeks later, James returned to the emergency department, following further episodes of vomiting and was admitted to a medical ward. The practice development nurse for people with learning disabilities was automatically alerted to his admission. They then visited the ward, and met the ward sister and the learning disability ward champion. The ward sister identified that the care home had written down some of James's likes and dislikes, which the ward team found useful.

The 4C framework provided a basis for the adjustments required. The ward sister and practice development nurse identified that use of The Hospital Communication Book and the My Healthcare Passport would be important to augment communication with James by enabling understanding.

It was identified that an endoscopy was required. Collaborative work was required between the doctor, the nursing staff, care workers and James to establish his ability to make an informed decision about this procedure. The Hospital Communication Book was used to aid communication. James appeared concerned and pointed to his mouth. The care worker identified that James likes to take care of his teeth and that this might be causing anxiety. It was agreed to leave The Hospital Communication Book with James and his care workers.

The doctor returned the next morning to conduct a capacity assessment. The doctor's notes reflect the complex adaptations required to communicate with James and other partners in James's care; this was significant in the debate about James's capacity to make an informed decision about having the endoscopy. James had clearly understood the information offered the previous day and had retained it. He was anxious about the camera going into his mouth and damaging his teeth, and expressed that he did not want the procedure. This provided evidence of an effective assessment of James' capacity.

Conclusion

Hospital staff encounter many challenges in caring for people with learning disabilities, as do people with learning disabilities. The law requires that reasonable adjustments are made for patients with learning disabilities when accessing hospital services. However, there is little best practice guidance available for hospital staff to enable these adjustments to be made. Practice development methods are a powerful tool to enable healthcare professionals to contribute to expanding the knowledge base and engage in implementing evidence in practice. The 4C framework has modelled methods of consultation and facilitation through its development, which encourage staff participation to reflect, learn and contribute in a meaningful way. There are opportunities to apply, study, reflect on and adapt these methods in different practice settings and patient groups.

The 4C framework for making reasonable adjustments for people with learning disabilities in hospital is comprised of four themes: communication, choice-making, collaboration and coordination. It enables hospital staff to provide care that is person-centred, safe and effective.

References

Atkinson D, Boulter P, Hebron C et al (2014) Exposure to health inequalities as a measure of outcome. Learning Disability Practice. 17, 1, 20-24.

Bhaumik S, Watson JM, Thorp CF et al (2008) Body mass index in adults with intellectual disability: distribution, associations and service implications: a population-based prevalence study. Journal of Intellectual Disability Research. 52, 4, 287-298.

Carney T (1991) Fourth generation evaluation. Canadian Journal of Communication. http://cjc-online.ca/index.php/journal/article/view/612/518 (Last accessed: 22 December 2016.)

Cheshire West and Chester Council v P [2014] UKSC 19, [2014] MHLO 16.

Clear Communication People (2014) The Hospital Communication Book. www.communicationpeople.co.uk (Last accessed: 22 December 2016.)

Cumella S, Martin D (2000) Secondary Healthcare for People with a Learning Disability. www.a2anetwork.co.uk/wp-content/uploads/2010/01/Secondary-Healthcare-for- eople-with-a-Learning-Disability.pdf (Last accessed: 22 December 2016.)

Department of Constitutional Affairs (2007) Mental Capacity Act Code of Practice. The Stationery Office, London.

Department of Health (2000) The NHS Plan: A Plan for Investment, A Plan for Reform. The Stationery Office, London.

Department of Health (2001) Valuing People: A New Strategy for Learning Disability for the 21st Century. The Stationery Office, London.

Department of Health (2003) Action for Health, Health Action Plans and Health Facilitation: Detailed Good Practice Guidance on Implementation for Learning Disability Partnership Boards. The Stationery Office, London.

Department of Health (2009) Equal Access? A Practical Guide for the NHS: Creating a Single Equality Scheme that Includes Improving Access for People with Learning Disabilities. The Stationery Office, London.

Disability Rights Commission (2006) Equal Treatment: Closing the Gap: A Formal Investigation into Physical Health Inequalities Experienced by People with Learning Disabilities and/or Mental Health Problems. http://disability-studies.leeds.ac.uk/files/library/DRC-Health-FI-main.pdf (Last accessed: 22 December 2016.)

Dixon-Wood M, Agarwal S, Jones D et al (2008) Synthesising qualitative and quantitative evidence within systematic review. In Watson R, McKenna H, Cowman S et al (Eds) Nursing Research: Designs and Methods. Churchill Livingstone Elsevier, Philadelphia PA, 89-100.

East Kent Hospitals University NHS Foundation Trust (2012) My Healthcare Passport. www.ekhuft.nhs.uk/patients-and-visitors/about-us/people-with-learning-disabilities/my-healthcare-passport (Last accessed: 22 December 2016.)

Emerson E, Baines S (2010) Health Inequalities and People with Learning Disabilities in the UK: 2010. www.improvinghealthandlives. org.uk/uploads/doc/vid_7479_IHaL2010-3HealthInequality2010.pdf (Last accessed: 22 December 2016.)

Emerson E, Hatton C, Robertson J et al

(2012) People with Learning Disabilities in England 2011. www.improvinghealthandlives. org.uk/publications/1063/People_with_ Learning_Disabilities_in_England_2011 (Last accessed: 22 December 2016.)

Francis R (2013) Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry. Volume Three: Present and Future Annexes. www.gov.uk/government/uploads/system/uploads/attachment_data/file/279121/0898_iii.pdf (Last accessed: 22 December 2016.)

Giraud-Saunders A (2009) Equal

Access: A Practical Guide for the NHS: Creating a Single Equality Scheme that Includes Improving Access for People with Learning Disabilities. http://webarchive.nationalarchives.gov.

uk/20130107105354/http:/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/

DH_109753 (Last Accessed: 22 December 2016.)

Green R, Bruce M, Finn P et al (2015) Independent Review of Deaths of People with a Learning Disability or Mental Health Problem in Contact with Southern Health NHS Foundation Trust April 2011 to March 2015. www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf (Last accessed: 22 December 2016.)

Guba E, Lincoln Y (1989) Fourth Generation Evaluation. Sage Publications, Newbury Park CA.

Health Quality Improvement Partnership

(2015) Learning Disability Mortality Review Programme. www.hqip.org.uk/national-programmes/a-z-of-clinical-outcome-review-programmes/learning-disability-mortality-review-programme (Last accessed: 15 December 2016.)

Heslop P, Blair P, Fleming P et al (2013) Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD). www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf (Last accessed: 22 December 2016.)

Manley K, McCormack B, Wilson V (Eds)

(2008) International Practice Development in Nursing and Healthcare. Blackwell Publishing, Oxford.

Manley K, Hills V, Marriot S (2011) Person- centred care: Principle of Nursing Practice D. Nursing Standard. 25, 31, 35-37.

Manley K, O'Keefe H, Jackson C et al (2014) A shared purpose framework to deliver person-centred, safe and effective care: organisational transformation using practice development methodology. International Practice Development Journal. 4, 1, article 2.

MacArthur J, Brown M, Hayes M et al (2010) Learning Disability Liaison Nursing Services in South East Scotland: A Mixed Methods Impact and Outcome Research Study. NHS Lothian, Scotland.

McCormack B, McCance T (2010) Person-Centred Nursing; Theory and Practice. Wiley-Blackwell, Chichester.

Mencap (2007) Death by Indifference: Following up the Treat Me Right Report. Mencap, London.

Mencap (2012) Death by Indifference: 74 Deaths and Counting. A Progress Report 5 Years On. Mencap, London.

Michael J (2008) Healthcare for All: Report of the Independent Inquiry into Access

to Healthcare for People with Learning Disabilities. The Stationery Office, London. Monitor (2015) Risk Assessment Framework. Monitor, London.

Parliamentary and Health Service Ombudsman (2009) Six Lives: The Provision of Public Services to People with Learning Disabilities. Part One: Overview and Summary Investigation Reports. www.ombudsman. org.uk/__data/assets/pdf_file/0013/1408/six-lives-part1-overview.pdf (Last accessed: 14 December 2016.)

Royal College of Nursing (2013) Meeting The Health Needs of People with Learning Disabilities: RCN Guidance for Nursing Staff. RCN, London.

Rycroft-Malone J (2013) How you might

use PARIHS to deliver safe and effective care. In McCormack B, Manley K, Titchen A (Eds) Practice Development in Nursing and Healthcare. Second edition. Wiley-Blackwell, Chichester, 130-145.

Tuffrey-Wijne I, Goulding L, Giatras N et al (2014) 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. doi:10.1136/ bmjopen-2013-004606.

Turner S, Robinson C (2011) Reasonable Adjustments for People with Learning Disabilities: Implications and Actions

for Commissioners and Providers of Healthcare. Evidence into Practice Report No.3. www.improvinghealthandlives.org.uk/uploads/doc/vid_11084_IHAL%202011%20 - 01%20Reasonable%20adjustments%20 guidance.pdf (Last accessed: 22 December 2016.)

Tyrer A (2015) Services: Reasonable Adjustments. www.stammeringlaw.org.uk/services/ra.htm#group (Last accessed: 22 December 2016.)

United Nations (2006) Convention on the Rights of Persons with Disabilities. www. un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html (Last accessed: 22 December 2016.)

Walker C, Beck CR, Eccles R et al (2014) Health inequalities and access to health care for adults with learning disabilities

in Lincolnshire. British Journal of Learning Disabilities. 44, 1, 16-23.