

Manchester Learning Disability Partnership

Access to secondary healthcare for people who are learning disabled

Project Report

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Summary

Background

People who are learning disabled have greater healthcare needs and more unmet health needs than the general population and therefore an increased attendance and admittance to acute general hospitals. Research suggests that mainstream health services can find it difficult to provide an equitable service for people who are learning disabled. The majority of research over the previous two decades has focused on primary healthcare; it is only in the previous few years that access to secondary healthcare services has been highlighted as a major issue warranting further research and intervention. In addition, there is a need to collate information about the initiatives being developed nationally to improve access to secondary healthcare services for people who are learning disabled.

Therefore, a six-month research and service development project was established in Manchester. The project aimed to identify issues relating to access to secondary healthcare for people who are learning disabled, and to help improve health access and inclusion within secondary healthcare settings and acute sector trusts for people who are learning disabled.

Methods

The project consisted of three main components:

Stage 1: A literature review to (i) identify the issues relating to access to secondary healthcare for people who are learning disabled; and (ii) to explore initiatives which have been established to help improve services for people who are learning disabled.

Stage 2: Information gathering about projects established to improve access to secondary healthcare for people who are learning disabled. This stage involved collecting grey literature, tools and resources and liaising with relevant healthcare professionals.

Stage 3: Collaborative working by the Manchester Learning Disability Partnership and the University Hospital of South Manchester NHS Foundation Trust (Wythenshawe Hospital) to improve local hospital provision for people who are learning disabled.

Local people who are learning disabled and carers were consulted throughout the project.

Key Findings

Literature review:

Eleven studies were identified relating to the issues around access to secondary healthcare for people who are learning disabled. In addition, three papers were identified which described initiatives such as learning disability liaison models and pre-admission assessments, and ten descriptive papers made recommendations to help improve the hospital care of people who are learning disabled. The majority of studies focused on the experiences of people who are learning disabled; carers; and general and/or student nurses.

Five key themes emerged from the literature review:

- Individual factors and the impact of the hospital visit
- The carer's role
- Attitudes, knowledge and communicative style of health staff
- Written information
- The physical environment.

The main recommendations from the literature focused on: changing systems; supporting the carer; providing guidance, education and training for hospital staff; improving information and making changes to documentation; improving the hospital environment; and the creation of new roles and teams.

Grey literature/resources:

Grey literature was gathered on a number of national initiatives to improve access to hospital services for people who are learning disabled. The key themes in the grey literature surrounded liaison models, communication and training.

A range of tools and resources were identified including: pre-admission assessments; traffic light assessments; guidance, policy and guidelines for hospital staff; resource packs for hospitals; hospital communication books; accessible information; and booklets for people who are learning disabled about going into hospital.

Discussions with health professionals in a liaison role:

Some of the key themes that emerged from people's experiences were:

- Liaison posts need to be permanent and are less successful as short term projects
- There is a need for extra funding to make these posts substantial rather than short term/pilot projects
- The liaison role needs to be strategic and educational rather than the provision of 'hands-on' nursing or personal care
- There is a need for a collaborative approach to designing tools, care pathways and procedures
- There is a need to formally evaluate liaison posts and the impact of initiatives on care.

Consultation with people who are learning disabled:

Twelve people who are learning disabled were asked about their experiences of hospital care in Manchester and their suggestions on how to improve their care in hospital. Four people had been admitted to a Manchester hospital in the last five years. They had a mixture of positive experiences (e.g. hospital staff were very nice and things were explained properly) and negative experiences (e.g. nurses did not listen; feelings of being lonely, scared and angry; and being isolated in a side room). All twelve people were asked to think about what would make their stay in hospital better and worse and this information was then used to adapt a 'Traffic Light' document that was being devised to aid the pre-admission process to Wythenshawe Hospital.

Collaboration between Manchester Learning Disability Partnership and Wythenshawe Hospital:

This was facilitated by earlier work locally and involved: meetings with senior health professionals from the hospital; the development of a 'Traffic Light' pre-admission document; the development of a learning disability guidance poster for hospital staff; and the development of an action plan for future work. An event is planned in Wythenshawe hospital to raise learning disability awareness for hospital staff and to launch the new tools and guidance.

Recommendations

A number of general recommendations have been made from this project including:

- Hospital services need to have a commitment to improving the hospital care of people who are learning disabled
- A permanent learning disability liaison post is needed to lead on the work for each hospital/area
- Local learning disability services need to work together to adopt a common approach to working with acute hospitals
- Systematic evaluations of liaison projects, tools and resources are needed
- Strategies need to be put into place to support family and carers
- People who are learning disabled and their carers need to be consulted at all levels of service provision and development.

More specifically in Manchester, there needs to be at least one liaison post for each of the three hospital trust areas to facilitate work in this area. Strong leadership across the areas covered by each liaison post needs to be provided in order to coordinate the work.

Introduction

This report is about a six month project which focused on how to improve access to hospital care for adults who are learning disabled. The project involved: reviewing existing literature on this topic; identifying tools and resources developed nationally to improve access to hospitals for adults who are learning disabled; consulting with adults who are learning disabled and carers in Manchester; and working closely with a Manchester hospital. This report describes the national and local context, gives details about how the project was carried out and outlines the findings from the project. Finally, the report makes a number of national and local recommendations for improving access to hospital services for adults who are learning disabled.

The healthcare needs of people who are learning disabled

Valuing People provides a clear policy direction in the United Kingdom regarding the care and support of people who are learning disabled, emphasising the rights, independence, choice and social inclusion of all people who are learning disabled and demonstrating a commitment to providing health and social care in mainstream services (Department of Health, 2001). The Disability Discrimination Acts 1995 and 2005 make it illegal to discriminate against disabled people in the provision of healthcare. All service providers have a duty to promote disability equality and to make reasonable adjustments to the way healthcare is delivered. Service providers must also adapt the physical features of healthcare settings to meet the needs of disabled people. NHS organisations also have a duty to produce a disability equality scheme to demonstrate and report on how they will tackle disability equality and how they will consult with disabled people within service design.

The recent report 'Equal Treatment: Closing the Gap' demonstrated that people who are learning disabled experience health inequalities when compared with the general population (Disability Rights Commission, 2006). People who are learning disabled have greater healthcare needs, have more unmet healthcare needs, experience an inferior quality of health with regards to both acute and chronic illness, and are at greater risk of developing health problems at an earlier age and dying earlier than the general population (Disability Rights Commission, 2006; Fernando, Cresswell, & Barakat, 2001; Janicki et al., 2002). Although the range of health conditions does not vary significantly from the general population, people who are learning disabled have a higher risk of coronary heart disease and are three times more likely to die from respiratory disease (Elliot, Hatton, & Emerson, 2003). People who are learning disabled also experience a greater prevalence of certain health conditions such as gastrointestinal disorders, pneumonia, sensory impairments, epilepsy, dental disease and osteoporosis (Barr, Gilgunn, Kane, & Moore, 1999; Center, Beange, & Mc Elduff, 1998; Cooke, 1997; Jansen, Krol, Groothoof, & Post, 2004).

Access to healthcare services by people who are learning disabled

Due to their experiences of both acute and chronic illness, people who are learning disabled have an increased attendance and admittance to acute general hospitals: an estimated 26% of people who are learning disabled are admitted to hospital every year, compared with 14% of the general population (Band, 1998). Since the resettlement of many learning disabled people into the community from long-stay hospitals, responsibility for their healthcare needs has rested with mainstream primary and secondary care providers. However, research has suggested that mainstream health services have had difficulty in providing an equitable service to people who are learning disabled, when compared to the general population (Barr et al., 1999; van Schroyen Lantman-de Valk, 2005). The United Kingdom government White Paper 'Valuing People' made recommendations to address this issue and highlighted the need for a change in service provision for people who are learning disabled (Department of Health, 2001).

The majority of research on access to healthcare for people who are learning disabled published in the previous two decades has focused on primary healthcare (for example, Bollard, 1999; Kerr, Fraser, & Felce, 1996; Lennox, Nadkarni, Moffat, & Robertson, 2003; Thornton, 1996). It is only over the last few years that access to secondary healthcare for people who are learning disabled has been highlighted as a major issue in need of further research and intervention. The recent report 'Death by Indifference' brings the importance of access to secondary healthcare to the forefront, presenting six case studies of people who Mencap believe have died prematurely, due to institutional discrimination within the NHS and neglect (Mencap, 2007). The National Patient Safety Agency (2004) also identified the vulnerability of people who are learning disabled in general hospitals and found that they are at an increased risk of harm whilst in acute hospital care. Particular areas of concern and potential risk factors were: communication difficulties; lack of learning disability training for health staff; additional health concerns such as epilepsy not being recognised by the hospitals; the assumption by general hospital staff that learning disability staff and carers can provide full nursing care; and issues around consent (National Patient Safety Agency, 2004).

While the evidence base on access to general hospital settings by people who are learning disabled is evolving, this area is still under-researched and requires further investigation. In addition, a number of NHS Trusts across the country have begun to develop initiatives to help improve access to secondary healthcare for people who are learning disabled. It is important that information about such service developments is collated and shared nationally so that hospitals and learning disability services are aware of ways of improving access to hospitals for people who are learning disabled. This project represents an initial attempt to summarise existing research and service initiatives in this area.

Project aims and objectives

The aim of this six-month research project was to identify the issues relating to access to secondary healthcare for people who are learning disabled, and to help improve health access and inclusion within secondary healthcare settings and acute sector trusts for people who are learning disabled.

The main objectives were:

- To identify and review national literature about access to acute services by people who are learning disabled.
- To identify and review literature on initiatives/interventions which have been established in the United Kingdom to improve access to secondary healthcare for people who are learning disabled.
- To identify and explore established areas of good practice in the North West of England.
- To identify information about the issues relating to access to secondary care in the North, Central and South Manchester hospitals.
- To work in one or more of the Manchester hospitals and develop recommendations to help improve the services for learning disabled people.

Methods

The project consisted of three main components. The first stage involved a literature review to: (i) explore the issues relating to access to secondary healthcare for people who are learning disabled; and (ii) identify initiatives which have been established to help improve services for people who are learning disabled. The second stage involved identifying and following up on specific projects both nationally and in the North West region by contacting the relevant healthcare professionals involved. The third stage concerned focusing on the hospitals in the Manchester area, and working with one of these hospitals to gather information about the issues relating to access to secondary healthcare, and to develop recommendations to help improve access for people who are learning disabled. People who are learning disabled and carers in Manchester were also consulted throughout the project.

Stage 1: Literature review

This stage involved a comprehensive literature search for all studies carried out in the United Kingdom relating to secondary healthcare/acute services and people who are learning disabled. The literature review focused on studies which were published between 1990 and 2007 in peer reviewed English language journals. The year 1990 was chosen to begin the search as this was when most of the large learning disability hospitals began to close down following the community care reforms.

The search used the following electronic databases: Cinahl, Medline and PsychInfo. These bibliographical databases were searched using a number of key terms such as 'hospital', 'secondary care', 'acute services', 'healthcare', 'intellectual disability', 'intellectual disabilities', 'learning disability' and 'learning disabilities'. Further literature was identified via the citations of papers identified from the initial search (snowballing), and a general internet search using the same key words. A systematic review and evaluation of the literature was then carried out to determine relevance and value. In addition, the National Research Register was also used to identify relevant ongoing and completed research projects which have not yet been published (grey literature). Messages were also placed on the North West Health Network and the UK Health and Learning Disability Network (distribution lists)¹, to find out about any other initiatives/interventions which may have been relevant to the project.

¹ The UK Health and Learning Disability Network is managed by the Foundation for People with Learning Disabilities, and is open to anyone with an interest in health and learning disability issues. The network aims to assist health practitioners in both mainstream and specialist services with the health and learning disability agenda and as such concentrates on problem solving, information sharing and networking.

Relevant websites were also browsed to help contribute to the work e.g. the A2A (access to acute)² link on the National Network for Learning Disability Nurses website and the Mencap website.

Stage 2: Contacting healthcare professionals involved in projects nationally and in the North West

This stage involved contacting health professionals to gather further information about specific projects nationally and in the North West and to find out:

- (i) whether projects and interventions have improved access to secondary healthcare and had long-term benefits for people who are learning disabled;
- (ii) whether projects and interventions have continued on a long term basis; and
- (iii) whether recommendations from local research projects and evaluations have been implemented and whether other changes have arisen from carrying out research and evaluation in this geographical area.

A range of 'grey' literature was gathered on access to hospital services for people who are learning disabled, including: service reports; audits; dissertations/thesis and PowerPoint presentations from different NHS Trusts across the country. Tools and resources were also identified.

Health professionals were identified through the initial literature search, as authors of papers relevant to the project area. Messages were placed on the North West Health Network and the UK Health and Learning Disability Network asking people working to improve access to hospitals to contact the researcher to share the outcomes of their work. People were also identified through the National Research Register and from work which had been cited as examples of good practice on the A2A and Mencap websites. Finally, other health professionals were identified from networking and liaising with colleagues and professionals already working in this area.

People were initially contacted via email, telephone call or letter. Relevant information was posted or emailed to the researcher. The researcher attended a number of meetings (for example the Access to Acute Network/North West Health Network meetings and the Pennine Acute Trust Hospital liaison nurse meetings). The researcher also arranged meetings with six health professionals in learning disability hospital liaison roles from across the North West region, to find out more about their roles and the specific projects and work that they are involved with.

² The A2A network was formed in 1998 and has expanded to become a national network for people who support people with a learning disability when they are in the general hospital. The network is concerned primarily with the issues surrounding people with a learning disability, their carers and staff in the general hospital.

Stage 3: Working with hospitals in the Manchester area and consultation with local people who are learning disabled and carers

Identifying previous work

This stage involved gathering information about the issues relating to access to secondary healthcare services in Manchester and finding out about any specific interventions that have been put into place in the hospitals in North, Central and South Manchester. This involved speaking to Manchester Learning Disability Partnership health and social care professionals and looking back at work undertaken by previous colleagues in this area, by reading their project reports, reflecting on the work already carried out in the Manchester hospitals, and discussing the projects with the staff involved.

Consultation with people who are learning disabled and carers

Learning disabled people were consulted with throughout the project. The researcher attended two 'Think Quality'³ focus group meetings, which were vital in enabling the researcher to find out about people's experiences of being admitted into the Manchester hospitals, and some of the issues that they felt strongly about. At the two meetings there were twelve learning disabled people present to discuss their experiences of hospital care. They were asked to consider 3 questions:

'What would make their stay in hospital better?'

'What would make their stay worse?'

'What would the hospital staff need to know about them?'

'Think Quality' group members were also asked to comment on the accessibility of a document being produced to provide hospital staff with information about patients. Parents and carers also provided feedback on this document. The feedback was used to make adaptations to the document.⁴

Collaboration with Wythenshawe Hospital

The final stage of the project involved meeting with senior health professionals from Wythenshawe Hospital to discuss collaborative working between the University Hospital of South Manchester NHS Foundation Trust and Manchester Learning Disability Partnership. The Trust incorporates both Wythenshawe and Withington Hospitals and provides a wide range of health services including: general medical, surgical, maternity and emergency services. The Trust has a total of 855 beds and last year delivered care to 420,000 people. It has several leading fields of specialist expertise including: Cardiology and cardiothoracic surgery; North West Lung Centre; Burns and plastic surgery; Breast care services; Stroke services and rehabilitation; and a

³ 'Think Quality' are an established group of learning disabled people in Manchester, who review quality and service issues such as: transport, bullying and healthy living. They have been meeting since early 2000, and there is now a core group of 12 people who attend regularly.

⁴ The document is the 'Traffic Light' and is discussed in detail later in this report.

Transplant Centre for heart and lung transplantation. In addition, the Trust is a major centre for training, education and research.

For the current project, the researcher was able to build on existing links with senior health professionals from Wythenshawe Hospital which had been developed by previous colleagues. These links facilitated liaising with the hospital and creating an action plan for joint working to help improve the experiences and care of people who are learning disabled who access Wythenshawe Hospital.

Findings

The findings are presented in five sections:

Section A provides a summary of the literature review findings on access to secondary healthcare for people who are learning disabled;

Section B provides the main findings from across the United Kingdom, in terms of the work being carried out and the grey literature/resources that are available;

Section C provides a summary of the outcomes from the discussions with North West health professionals;

Section D summarises the findings from consultation with people who are learning disabled; and

Section E provides details of a local project involving collaborative working between Manchester Learning Disability Partnership and Wythenshawe Hospital.

Section A: A summary of the literature review findings

The literature search identified eleven studies relating to issues around access to secondary healthcare/acute services for people who are learning disabled. The search also located three other papers describing initiatives developed by NHS Trusts across the United Kingdom to help improve access to secondary healthcare for people who are learning disabled. These initiatives included two Hospital Liaison Nurse posts (Stoke and Edinburgh), a pre-admission assessment (Edinburgh) and an Acute Hospital Liaison Project (Birmingham). The search also identified ten descriptive papers which provided further recommendations to help improve the general hospital care of people who are learning disabled.

The majority of studies included in the literature review focused on the experiences and perspectives of three groups of people: people who are learning disabled; carers; and general and/or student nurses. Two studies also gained the views of other hospital staff and community learning disability nurses.

A number of themes were apparent within and across the studies concerning: (i) individual factors and the impact of the hospital visit on people who are learning disabled; (ii) the carer's role; (iii) the attitudes, knowledge and communicative style of health staff; (iv) written information; and (v) the physical environment. The main issues and specific recommendations and examples of good practice are shown in Table 1.

Table 1: Key themes relating to access to secondary health care for people who are learning disabled (PWLD)

Key themes	Barriers	Examples of good practice and recommendations
<i>Individual factors and the impact of the hospital visit on people who are learning disabled</i>	A range of factors can lead to PWLD becoming bored, distressed, anxious, angry, and/or frustrated. These include fear about going into hospital, long waiting times, lack of age appropriate activities, feeling ignored by hospital staff, and poor communication about tests and treatments (Glaysheer, 2005; Hart, 1998)(Hart, 1998; Glaysheer, 2005; Browne, 1999; Fox & Wilson, 1999; Cumella & Martin, 2004). PWLD are not always asked if they want a carer to remain with them (Glaysheer, 2005). Hospitals may not meet individual needs around feeding (e.g. soft food, vegetarian options for people with special dietary requirements) and continence (e.g. help going to the toilet or continence products) (Fox & Wilson, 1999).	<i>Preparing the patient for admission e.g. the use of videos, accessible information, books, desensitization programs, pre-admission visits and pre-admission assessments (Barr 1997; Bolland & Jones 2002; Brittle 2004; Cumella & Martin, 2004; Hannon 2004).</i> <i>Reviewing appointment systems e.g. using 'positive discrimination' to reduce waiting times; allocating longer appointment times; and ensuring suitable facilities are available such as a side room or extra staffing if necessary (Bolland & Jones 2002; Browne 1999; Lindsey et al 1993).</i> <i>The importance of collaborative working and working as a co-ordinated team involving the PWLD, family/carers, hospital staff and community learning disability specialists (Barr 1997; Brittle 2004; Brown & McArthur 2006; Cumella & Martin 2004; Hannon 2003; Hart 1998; Hunt et al 2004; Lindsey et al 1993).</i>
<i>Carer's role</i>	Carers are not always recognised as a valuable member of the health team. Their knowledge about the PWLD and concerns about hospital care may be ignored (Browne, 1999). In contrast, there can be over-dependence on the carer both as a source of knowledge about the person and as the person to provide consent on the PWLD's behalf	<i>Nurses demonstrating positive regard for the role of the carer and their knowledge about the PWLD (Sowney & Barr, 2006).</i> <i>Providing relatives and carers with information (e.g. about the patient's illness, procedures); understanding and support (e.g. emotional and physical support when carers need breaks for meals and to go to the toilet), to</i>

	(Sowney & Barr, 2006). Carers can be expected to be with the PWLD at all times and to provide long-term support, including physical nursing care (for example, washing and dressing the patient, changing the bed and administering medication) because they perceive that hospital staff do not have time to do these tasks (Fox & Wilson 1999). However, carers may receive little assistance from hospital staff and no access to hospital facilities (Bollands & Jones, 2002; Cumella & Martin, 2004; Fox & Wilson, 1999).	<i>enable them to be of help to the patient and the hospital team (Lindsey, Singh, & Perrett, 1993).</i> <i>Carers being able to stay in hospital with PWLD and accompany the person whilst undergoing procedures (Bollands & Jones, 2002; Fox & Wilson, 1999).</i> <i>Strategies to improve support for carers who stay with the patient in hospital, such as extra staffing to meet additional support needs (Bollands & Jones, 2002).</i>
<i>Attitudes, knowledge and communicative style of health staff</i>	Carers often report feeling that health staff lack the necessary skills and knowledge to meet the needs of PWLD (Bollands & Jones, 2002; Fox & Wilson, 1999). Nurses and therapists also report lacking confidence and knowledge when working with PWLD and do not know how to access expert advice (McConkey & Truesdale, 2000; Sowney & Barr, 2006). Health staff may lack understanding of issues relating to consent and carers' role in providing consent (Hart, 1998; Sowney & Barr, 2006). PWLDs feel ignored by hospital staff (Cumella & Martin, 2004). Health staff may talk to the carer before the PWLD (Hart, 1998). Communication and advice about treatment, procedures, medication and discharge can be unclear and complicated (Hart, 1998; Browne, 1999; Glaysheer, 2005).	<i>There is a need for guidance, education and training for hospital staff on basic learning disability awareness and the corresponding health needs (Cumella & Martin, 2004; Slevin 1995; Slevin & Sines, 1996; McConkey & Truesdale 2000; Sowney & Barr 2006) – including user-led training (Hart, 1998) and resource packs for wards and departments (Bollands & Jones, 2002).</i> <i>Evidence suggests that nurses who have experience working with PWLDs and specific training will have more positive attitudes (Slevin, 1995; Slevin & Sines, 1996).</i> <i>It is important that health staff speak directly to the PWLD, and that they introduce themselves and explain their roles (Glaysheer, 2005). Use of pictures, photographs and symbols to explain procedures is</i>

		beneficial, as are tools such as 'the Hospital Communication Book' (Brown & McArthur 2006; Glaysher, 2005).
Written information	Standard patient information gathering tools do not collect enough in-depth information to formulate a comprehensive care plan (Bollands & Jones, 2002). Written information and instructions may use small font which is difficult to read, be poorly laid out, unclear and confusing (Glaysher, 2005).	<i>Changes to documentation are recommended, such as specialist GP referral forms; accessible and user friendly information forms illustrated with pictures and diagrams; and the use of specialist assessment tools for pain and distress (Bollands & Jones 2002; Brown 2005; Brown & McArthur 2006; Cumella & Martin 2004; Glaysher 2005; Hannon 2003; Hart 1998).</i> <i>Development of pre-admission procedures (Hannon, 2003). Early identification of needs and gathering of information about the person – i.e. through pre-assessment questionnaire, and improving patient information brought into hospital. Examples include communication passports, traffic light assessments and information packs about the PWLD (Hart, 1998; Bollands & Jones, 2002; Cumella & Martin, 2004; Hannon, 2003).</i> <i>Adapt X-ray procedures and techniques (Browne, 1999).</i> <i>Enhanced triage system in A&E (Hannon, 2003).</i> <i>Provision of accessible information about choices is recommended, such as the use of symbols/pictures when choosing meals (Cumella & Martin, 2004).</i>

<i>Physical environment</i>	Confusing signage and maps can lead to difficulties navigating the hospital site. The physical environment in clinical services may be cluttered and the layout of chairs may be poor, hindering accessibility and creating a negative experience (Glaysher, 2005). Lack of appropriate equipment for lifting and handling to allow examination and care for people with severe and profound learning disabilities and/or severe physical disabilities (Brown 2005; NPSA 2004). There are advantages and drawbacks associated with whether the PWLD is allocated a side room or placed on a ward (Fox & Wilson, 1999).	The use of pictures and art around the hospital help to create a friendly environment (Glaysher, 2005). Improvements to hospital environment through the use of colour codes, symbols and special equipment (Cumella & Martin, 2004). Waiting and consulting areas could be improved to make them more welcoming and accessible for PWLDs e.g. incorporating colours and lighting which minimise the potential for distress (especially for people with Autism) (SCLD 2004).
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The concept of a specific worker or team to improve access to hospital services for people who are learning disabled has also received a large amount of attention in the literature. For example, some authors recommend the establishment of learning disability liaison nurses to assist with a patient's direct care, offer support to relatives and carers, and to educate ward staff (Foster 2005; Hannon 2003; NPSA 2004). An alternative approach is an Acute Hospital Liaison Project consisting of a number of staff; for example, a team of two community nurses and three support workers was created in Birmingham (Glasby 2002, 2003). Key tasks carried out by the project team included: providing advice and training to hospital staff (e.g. consent and communication); accompanying people who are learning disabled on pre-admission visits; educating people who are learning disabled to prepare them for admission; supporting patients and allowing carers to take a break; and facilitating community support prior to discharge. Other liaison models recommended include: extending the role of community learning disability nurses within hospitals, developing link nurse schemes and the creation of a nurse consultant post to facilitate a citywide approach to providing coordinated care across multi-site hospitals (Bollands & Jones 2002; Brown & McArthur 2006).

Section B: The main findings about national work to improve access to secondary healthcare in the UK

A number of contacts were made with health professionals across the UK through the searches of websites, the National Research Register and the messages posted on the North West Health Network and the UK Health and Learning Disability Network. The researcher liaised with these health professionals to find out about their work on learning disabilities and acute general hospitals. As a result a range of literature was collated from different NHS Trusts across the country, including service reports, audits, dissertations/thesis and PowerPoint presentations (grey literature). A range of tools and resources was also collected.

The grey literature gathered was produced over a ten year period (1997 - 2007). The majority of the work was descriptive (i.e. describing the background to and providing details about projects and/or discussing the issues relating to hospital access for people who are learning disabled). Whilst some of the grey literature presented findings from audits and focus groups, few reports and audits provided a thorough evaluation of the impact of projects.

The grey literature focused on three key themes: liaison models, communication and training. Some of the issues within each theme are outlined below. These issues are similar to those highlighted in the previous section on the literature review. The range of tools and resources being developed are also discussed. Appendix 1 gives more details about the content of the grey literature. A full list of tools and resources is provided in Appendix 2.

Liaison models

A number of liaison models have been set up or recommended to improve access to healthcare for adults who are learning disabled. These usually involve either a liaison post (usually a nurse) linked to a hospital, or a liaison team/service. Sometimes a person employed within the hospital has taken on a 'champion' role and leading on work. Whilst the post title may not always be liaison nurse, the post aims or roles are often similar (other job titles include 'health access nurse', 'learning disability project nurse'). These posts are usually set up as short term pilot projects and many are part-time. Evidence suggests that liaison posts can take up to three years to become established (Barnet, Rochdale). Some posts focus purely on access to secondary healthcare, whilst some posts focus on improving access to both primary and secondary healthcare services.

Nationally, information was provided about liaison nurse posts which have been set up in a number of areas: Fife in Scotland, Bristol, Essex (Colchester PCT has two liaison nurses and two nurse specialists are involved with the two local NHS acute trusts), Barnet, Shropshire, Rochdale, and Burnley. Sheffield and Londonderry have recommended that liaison posts be established. Two areas had a liaison team or service model: NHS Lothian acute liaison service and the Birmingham acute liaison project (Glasby, 2002, 2003; as referred to in the literature review).

The focus of these models has been on improving access to hospital services for people who are learning disabled and ensuring a more co-ordinated approach to service provision through the following means:

- Developing protocols, care pathways, guidelines for good practice
- Developing and adapting systems (e.g. 'trigger' or flagging systems to alert services that someone is learning disabled, pre-admission and discharge)
- Liaising with the Patient Advice and Liaison Services (PALS) within hospitals
- Developing resources (e.g. information and resources for hospital staff, traffic light systems, patient passports, accessible information for people who are learning disabled)
- Direct patient contact (e.g. preparation and planning before hospital consultation or admission, clinical advice, interventions, co-ordination, risk management, promoting, modelling and producing personalised accessible information)
- Training (see section below)

Evaluations are limited but have shown benefits from liaison posts. For example, a questionnaire survey in Barnet showed that in a six month pilot period the role led to immediate benefits for hospital staff, patients and the community trust.

Russ (2005) found that a previous learning disability project nurse post was highly valued and suggested that this had been the main catalyst in providing positive change.

Section C provides details of issues raised in discussions with people in liaison posts set up in the North West Region.

Communication

A number of reports within the grey literature reinforce the importance of improving communication: including an audit carried out at a hospital in Kent and focus groups with people who are learning disabled (Russ, 2005; Thornley, 2006). Three areas have been identified where communication could be improved:

- Between clinicians and patients who are learning disabled (Kent audit report, 2006)
- Between clinicians and carers (Kent audit report, 2006; Russ, 2005)
- Between hospital and community based services (Kent audit report, 2006)

Poor communication can result in staff having unclear expectations of the carer's role in supporting the person who is learning disabled whilst in hospital and can reflect a lack of staff knowledge, skill and confidence in working with people who are learning disabled (Russ, 2005). Poor communication can also mean that people who are learning disabled lack knowledge and understanding of what is happening whilst they are in hospital and hence experience a lack of control (Thornley, 2006). The grey literature also reinforces the need for accessible information for patients and for training around capacity and consent for staff.

Recommendations to improve communication include:

- Development of hospital guidelines for working with people who are learning disabled (Barnet)
- Development of toolkits and workbooks for hospital staff (Kent)
- Ensuring greater awareness of British Sign Language and Makaton (Kent)
- Improving accessible information – e.g. provision of CHANGE Picture Bank for staff (Thornley, 2006) (Kent, Shropshire)
- Develop and produce communication resources (Barnet)
- Development of assessment/checklist and guidelines for use with carers (Kent)
- Audits of opinions and experiences of people who are learning disabled and carers (Kent)
- Development of methods of providing personal information about people who are learning disabled to hospital staff (e.g. Traffic Light Hospital Care Plan (Kent); Hospital Book (Barnet); Patient Passports / client records (Shropshire))

- Creation of permanent learning disability liaison nurse post (Russ, 2005) (Kent)
- Training and awareness raising for hospital staff: in particular on the needs and experiences of people who are learning disabled, communication and consent (Kent, Barnet)
- Revising signage (Thornley, 2006)
- Improving planning and provision of emotional support so that disabled people feel more in control (Thornley, 2006)

Improving communication and information for people who are learning disabled can also lead to benefits for other patient groups, such as people who have had a stroke, older people and people for whom English is their second language (Barnet).

Training

Training for hospital staff has been highlighted as a need within the published and the grey literature. The grey literature describes and evaluates a variety of training initiatives carried out nationally. Training has covered: definitions of learning disability, policy, communication, access, consent, physical health needs, action planning and the role of learning disability services. User groups and organisations such as Mencap and the Down's Syndrome Association have been involved in training.

There are a range of ways that training can be delivered. Hampshire organised a week of training during learning disability awareness week. Other areas have recommended an ongoing programme of education and training in the form of awareness raising exercises and accredited and commissioned short courses (Rochdale, Londonderry). Training is rarely mandatory and a number of reports have recommended that this should form mandatory training for all hospital staff and in initial training. Training is needed for all hospital staff (i.e. receptionists, porters, registered nurses, health care assistants) (Rochdale). Fife now provides training at staff induction. There can be difficulties getting staff released from wards, especially for longer courses and open training and awareness sessions may be poorly attended; an alternative is to provide shorter training sessions, if necessary on the wards (Salford, Bristol).

Evaluations of training have generally found that most participants report that training is very useful and that they can relate it to their practice (Hampshire, Bristol, Sheffield). After the training more respondents reported that symbols were available in their environment, that knowledge about learning disability and the learning disability team had improved, as had confidence in working with people who are learning disabled and consent issues were much clearer (Hampshire).

Tools and resources

In addition to the grey literature, several resources and tools were gathered from health professionals and websites. There is clearly an enormous amount of work being carried out nationally to improve the experience of hospital services for people who are learning disabled. The tools and resources being developed includes guidance and guidelines for hospital staff on supporting people who are learning disabled; pre-admission assessments; resource packs for hospital staff; traffic light assessments; accessible information booklets about going into hospital for people who are learning disabled; and hospital communication books. Appendix 2 provides a full list of tools and resources.

Section C: Summary of the outcomes from discussions with North West health professionals in a learning disability hospital liaison role

The researcher arranged meetings with six health professionals in learning disability hospital liaison roles from across the North West region, to find out more about their roles and the specific projects and work that they are involved with. The five areas visited were: Oldham, Blackburn, Trafford, Burnley, and Salford.

A number of key themes emerged from the discussions:

- The experiences of those who had held hospital learning disability liaison posts suggested that such posts need to be long-term / permanent, and are less successful as short term projects.
- People felt that there is a need for extra funding for learning disability hospital liaison roles to make them substantial posts rather than short-term or pilot projects.
- Funding arrangements are not consistent. Whilst the majority of posts appear to be funded by Primary Care Trusts, one post had mixed funding from both community and hospital sources.
- It was felt that the liaison role needs to be strategic and educational and that the provision of 'hands-on' care should remain the responsibility of the hospital staff.
- There was some disagreement about where liaison posts should be based. Being based at the hospital is ideal for emergencies, but can be very isolating for the person in the liaison post. Being based in the Community Learning Disability Team can be less isolating and being based within such a multi-disciplinary team can provide a more holistic person-centred approach to service provision for people who are learning disabled.
- There was awareness that the liaison role may be different in each geographical area and that there is a need for a collaborative approach to

- designing tools, care pathways and procedures between community teams and the local hospitals.
- The postholders recognised the need to formally evaluate liaison posts and the impact of initiatives on care. Some of the postholders had developed action plans to take this forward.

Some of the work currently being undertaken by people in a learning disability liaison role across the North West includes:

- The development of a traffic light assessment, hospital discharge and information plan, and a vital information sheet.
- Pre-admission assessments.
- Training for hospital staff.
- The development of guidelines and information for hospital staff e.g. on capacity and 'best interests'.
- Matron's Guidance Packs/ Resource packs.
- Devising and adapting existing hospital policies e.g. admission and discharge.
- Assessment tool kits (e.g. patient health book, health record, A&E grab sheet).
- Making information accessible (e.g. pre-booking system, use of pictures and symbols and adapting the literature sent out to patients).
- Devising care pathways.
- Devising resources for people who are learning disabled (e.g. leaflets on having an operation).

Section D: Findings from consultation with people who are learning disabled

The researcher visited two 'Think Quality' meetings in February and March 2007. At each meeting there were twelve learning disabled people present, as well as two representatives from Manchester Learning Disability Partnership.

i) Experiences of hospital care

At the first meeting people were asked to tell the researcher if they had been admitted to a Manchester hospital in the last five years. Four out of twelve people had been admitted to Wythenshawe Hospital, St Mary's Hospital for women and children, and Manchester Royal Infirmary. These people spoke about their experiences as summarized below.

Example 1

The first person remembered going into hospital a few years ago. She recalled that she had gone into hospital on her own in an emergency ambulance. She stated that the reason for going into hospital was 'women's problems'. The lady could not recall many details from her stay in hospital, but did state that she had

been angry with the nurses because they did not listen to her, ignored her and when the nurses thought she couldn't hear them, she remembers that they 'called her names'.

Example 2

The second person told the researcher that she had been into hospital for just one day to have her teeth out. She said that she had gone to the dentist and told him that she had toothache. The dentist referred her to the hospital and said it would be best if she had all her teeth removed. The lady recalled that she had to be put to sleep for the operation, but when she woke up the staff were very nice to her and explained things so that she could understand them.

Example 3

The third person went into hospital less than two years ago. She recalled that she had collapsed in her house, and her mum phoned an ambulance. Then she collapsed again and when she woke up she was in hospital, where the doctor told her that she had been in a 'diabetic coma'. That was when she was first diagnosed with diabetes. The lady remembered that she had stayed in hospital for about nine or ten days and that the nurses were kind to her. But she did remember that the doctor spoke to her mum and not to her. The lady also remembered that she was on her own at night and very lonely because she was in a small room by herself, which was 'scary'.

Example 4

The fourth person that had been in hospital remembered staying there for five weeks when he was 'very poorly'. The man remembers that he had an operation on his leg which meant that he couldn't walk for a few weeks. He recalls being quite lonely when he was in hospital because he had no family and his carers didn't visit very often. He did think that the nurses and doctors were nice to him, but remembers that he didn't understand much of what they had to say.

The learning disabled people who told the group about their experiences of hospital care seemed to have mixed views.

Positive experiences:

- Staff were very nice
- Things explained properly
- Nurses were kind
- Nurses and doctors were nice

Negative experiences:

- Nurses did not listen
- Nurses ignored the person
- Nurses 'called the person names'
- Doctor spoke to the person's mum and not to her
- Isolated in a side room

- Not understanding much of what the nurses and doctors said
- Feelings of being lonely, scared, angry

Most of these experiences are similar to those reported in the studies included in the literature review discussed earlier. There are episodes of good care with positive appraisals of hospital staff and the way in which they have adapted their communication to explain things in an accessible way. However, examples of poor care and practice are still in existence as reported in the cases above. Most of the issues can easily be rectified if hospital staff are made aware of how they can adapt their communication style to help explain procedures to people who are learning disabled, and help them to feel included and not ignored.

ii) Suggestions to improve hospital care

At the second meeting the twelve people who are learning disabled were asked to imagine that they were in hospital alone with no family, carers or friends present. They were asked to think about how they would tell the nurses how to care for them and what they would say. More specifically they were asked to think about the following three questions:

- 1) What would make their stay in hospital better?
- 2) What would make their stay worse?
- 3) What would the hospital staff need to know about them?

This information was then used to adapt a 'Traffic Light' document that was being devised by the researcher to aid in the pre-admission process to Wythenshawe Hospital. This document will be described in more detail in Section E.

Some of the important areas that arose from the three questions were:

- Lists of things that would make people happy and sad in hospital
- What people would like to do (e.g. watch TV, listen to music)
- The things that people might like to eat and drink
- Lists of special routines that the people have
- Things that would make people feel safe in hospital
- How people like to be talked to (e.g. quietly, loudly, slowly)
- Things people would like to bring into hospital with them (e.g. favourite book, toy, game)
- People that they would like to visit them in hospital
- Things that would cheer people up
- Things that people are interested in (e.g. football and pets)
- Special medical requirements (e.g. how to take tablets and medication, if the person is on a diet, allergies etc)

Section E: Local collaborations between Manchester Learning Disability Partnership and local hospitals

This section of the report summarises both the previous work carried out to improve hospital services for learning disabled people in Manchester and the work carried out locally with Wythenshawe Hospital as part of this six-month project.

1. Previous work with the Manchester hospitals

Two previous projects worked to improve access to both primary and secondary healthcare services within Manchester (the Integrated Healthcare project (2001-2003) and the Health Access and Inclusion project (2005-2006)). Information was gathered from literature on these projects about specific interventions that have been put into place in the hospitals in North, Central and South Manchester. Several pieces of work were carried out with local hospital trusts as part of these projects as follows:

The Pennine Acute Hospitals Trust

A training package was developed and delivered to professional and non-professional staff at North Manchester General Hospital as an elective course and as part of wider training (e.g. NVQ). This training received very positive feedback.

The development of a 'flagging' system in A& E to alert staff that a person was learning disabled was discussed but this system had not been implemented by the end of 2006.

University Hospital of South Manchester NHS Foundation Trust (UHSMT)

A 'flagging' system was implemented in A& E to alert staff that a person was learning disabled as part of the first project.

A two day event was held at Wythenshawe Hospital in 2006 to raise awareness of learning disability issues. One day was with people who are learning disabled and the other day with staff.

Accessible booklets (e.g. going into hospital, having an operation and going into A&E) were devised by one of the project workers with Manchester Learning Disability Partnership Speech and Language Therapists. These booklets need updating and this piece of work is ongoing.

An action plan for future work was developed.

Central Manchester Hospitals

No projects have been carried out with Central Manchester Hospitals. This has been acknowledged as an area for future work.

Other relevant work

In depth interviews were carried out with five people who had used local health services, including hospital services (Chapman, Fedeczko, Fleming, Reed, & Starling, 2004).

An audit of hospital admissions and an evaluation of the planned hospital admission and discharge policy was carried out (Parvin & Chapman, 2006).

2. Collaboration with Wythenshawe Hospital

For the current project, the researcher built on existing links with senior health professionals from Wythenshawe Hospital (UHSMT) which had been developed by the previous projects. At the beginning of the current project the researcher attended a meeting at the hospital to discuss collaborative working and how to take the existing action plan forward. The action plan was reviewed and revised, and it was agreed that the key tasks for Manchester Learning Disability Partnership to progress were:

- Guidance to assist hospital staff in recognising people who are learning disabled;
- The development of a 'grab pack': it was agreed that the 'Traffic Light' patient held information document would be used to accompany the patient through all departments of the hospital;
- The development of Trust guidance for staff on supporting patients with a learning disability; and
- Updating the existing patient booklets.

It was decided that Wythenshawe hospital will hold a launch day in September 2007. This launch day will be used to raise learning disability awareness amongst hospital staff and to promote the new resources and tools that will be introduced onto all wards and departments. The planning of the launch and the content is ongoing. The tools and resources that have been devised for use by hospital staff which will be promoted at the launch are discussed below:

(i) Recognising Learning Disability

Wythenshawe Hospital requested some guidance on how to tell if a person is learning disabled, particularly for frontline hospital staff working in triage (A&E) and reception. A one-page sheet has been developed which offers guidance for hospital staff. This guidance includes questions which can be used to give an indication of whether someone has a learning disability and whether hospital staff should contact additional/specialist services. The questions have been developed from those suggested by the Royal College of Nursing (2006) and include:

- Did you go to a special school?
- Do you go to a day centre?
- Do you have a social worker, care manager or keyworker?
- Can you tell me where you live?
- Can you tell me the time? and
- Have you ever been supported by learning disability staff or lived in a learning disability hospital?

(ii) The 'Traffic Light'

The reviews of existing literature and tools/resources identified that the 'Traffic Light' document was a good practice example which could be used at the pre-admission stage. The original 'Traffic light' assessment document was devised by Gloucestershire Partnership NHS Trust and has been adapted by at least four other NHS Trusts across the United Kingdom. The document is appealing to hospital staff, people who are learning disabled and their carers because it is attractive, easy to fill out by the patient/carer, and easy and quick to read by the hospital staff. This was confirmed by consultation at 'Think Quality' meetings and through gaining feedback from Talbot House parent and carers in Manchester. The document is intended to be filled out prior to a hospital visit/admission by the person who is learning disabled and/or their carer, in order to help hospital staff to know more about the patient.

The researcher adapted the original version of the 'Traffic Light' document to make it more accessible to the person filling it out and for the staff who read it. This was achieved by including pictures and symbols, re-wording and changing some of the information to make it more up-to-date, and completely changing the final page. These revisions were informed by feedback from 'Think Quality' members and from Manchester Learning Disability Partnership and Wythenshawe Hospital staff.

The 'Traffic Light' is split into 3 sections:

- Red - 'Things you must know about me' (e.g. patient details, GP, medical history, consent, communication/understanding etc),
- Amber - 'Things that are really important to me' (e.g. risk/safety, level of support, seeing and hearing, mobility, taking medication etc), and
- Green - 'What you need to know about me' (e.g. things that will make my stay better and worse).

The 'Traffic Light' is due to go through Wythenshawe Hospital's Clinical Governance meeting in August 2007. The 'Traffic Light' document will be piloted with people who are learning disabled known to Manchester Learning Disability Partnership who are regularly admitted into hospital, including those who attend South Manchester Day Services and those who are supported by Manchester Learning Disability Partnership supported housing. Talbot House parents and

carers and North West Community Services are also keen to pilot the 'Traffic Light'. If this pre-admission document is successful the intention is to explore the possibility of introducing it across all Manchester hospitals.

(iii) 'Guidance for staff' poster

A poster has been developed to provide hospital staff with guidance on supporting people who are learning disabled who are admitted into hospital. This poster was also adapted from guidance originally produced by Gloucestershire Partnership NHS Trust. The original guidance took the form of a card for staff. Following feedback from Wythenshawe Hospital and Manchester Learning Disability Partnership staff, the researcher has changed some aspects of the guidance content and the guidance will be produced as an A3 poster designed to go on the walls of all wards and departments in the hospital. Wythenshawe Hospital have also agreed to make the poster into a pocket sized card to be given out at staff inductions.

The poster covers issues such as: learning disability definitions; questions to ask if you think a patient has a learning disability; and guidelines on communication, explanation, reducing anxiety and consent. The poster also has a section on how to gain further advice and support, and includes the telephone numbers of the local community learning disability teams and the Manchester Contact Service.

(iv) Learning Disability patient booklets

Three booklets: *Going to Hospital*, *Going to A&E*, and *Having an Operation* which were originally devised in 2003 are currently being updated by Manchester Learning Disability Partnership. These booklets offer a step by step explanation of the process and procedures involved in hospital care, and include a number of pictures, symbols and photographs to help the learning disabled person to understand. When these booklets are completed they will be available on the UHSM Trust website for people to download. Copies will also be available from health professionals from Manchester Learning Disability Partnership and may also be available on the Manchester Learning Disability Partnership and Manchester Primary Care Trust websites.

Recommendations

General recommendations for the care of people who are learning disabled in acute hospitals across the United Kingdom

- 1) Hospital services must be alert to the potential barriers facing people who are learning disabled when they are using hospital services. They need to give specific emphasis to improving access to hospital services for people who are learning disabled and the commitment to improve hospital care for people who are learning disabled needs to be of high priority.
- 2) Any work carried out to improve hospital care for people who are learning disabled needs to be supported at a senior level within hospitals.
- 3) Links need to be developed and maintained between hospital services and community learning disability services in order to facilitate effective collaborative working.
- 4) There is a need for a liaison post to lead on the work for each hospital/area. The role of the liaison post needs to be one of supporter and advisor to the hospital (for example, through provision of training and by developing tools and resources) rather than provision of basic nursing and personal care.
- 5) Projects which are set up to address the barriers to good hospital care need to be permanent and perceived as an ongoing important piece of work.
- 6) People working in a liaison role need to be aware of existing tools and resources that are available nationally to learn from other areas that have tried and tested methods. There needs to be a database of resources that is updated regularly.
- 7) Local learning disability services need to work together to adopt a common approach to working with acute hospitals in the same geographical area, in order to avoid overlapping on the same work and devising different systems which could confuse hospital staff.
- 8) A systematic evaluation of liaison projects, tools and resources needs to be established. Any evaluation needs to incorporate the views of people who are learning disabled and their carers.
- 9) Hospitals need to improve staff knowledge and attitudes about learning disability and staff communication with people who are learning disabled. Training is essential, but the type of training depends upon local circumstances. Various types of training have been used nationally, including learning disability awareness days, drop-in sessions, user-led training and resource packs for wards and departments.
- 10) Different departments within hospitals need to develop their own strategies to improve care for people who are learning disabled. For example Accident and Emergency departments could explore the possibility of operating a 'no wait' policy, whilst other departments need to review their appointment systems and to be aware that people who are learning disabled are likely to need more time for consultations and procedures.

- 11) Sensitive strategies need to be put in place to support carers and family members, such as: ensuring extra staffing is available to enable them to have breaks for meals and to go to the toilet; providing facilities to enable carers to stay in hospital over night; and providing relatives and carers with information about the patient's illness and procedures and keeping them informed at all stages. It is important to remember that whilst carers and family members are a vital source of knowledge and information about the patient, they should not be relied on to provide basic nursing/physical care.
- 12) People who are learning disabled and their carers need to be consulted at all levels of service provision and service development, including consultation, training and evaluation.

Specific recommendations for Manchester

Manchester is a complex area with three acute hospital trust areas: these incorporate seven adult acute hospitals, two children's hospitals and a specialist cancer hospital. There are approximately 1500 people who are learning disabled known to Manchester Learning Disability Partnership.

- 1) All of the national recommendations above directly apply to the position in Manchester.
- 2) Therefore, it is recommended that there should be at least one liaison post for each of the three hospital trusts to facilitate work in this area.
- 3) There needs to be strong leadership across the areas covered by each liaison post in order to coordinate the work.

Appendices

Appendix 1: Grey literature on access to acute for people who are learning disabled

Grey literature is in date order. Grey literature from the North West Region is highlighted in grey

Year	Type of document	Aims	Area/Service	Content	Evaluation
2007	Audit report on the Hospital Liaison Nurse	To evaluate the post of hospital liaison nurse for learning disabilities, questionnaires were sent out to hospital staff within Rochdale Infirmary, and to clients who had been supported in a residential care setting and who may have self-referred, or been referred by a third party.	Rochdale	16 out of 25 questionnaires were returned by <i>hospital staff</i> . To summarise, 87.5% were aware of the liaison nurse; 44% thought the role was useful e.g. in assisting in assessment and discharge planning, providing accessible information, providing support etc (some said they hadn't used the service so not applicable); 75% said they were provided with information such as posters with contact details on, visits to the ward etc, and 38% has attended LD training and found it useful.	YES- Recommendations: <i>For hospital staff-</i> 1) The role of the liaison nurse can take up to 3 years to be established e.g. Oldham PCT, therefore the role in Rochdale needs to continue 2) At present the role has only touched on the baseline of needs, therefore a more in-depth approach is required e.g. making stronger links with wards/clinic areas. 3) Training needs to continue on a rolling programme to ensure all staff have some awareness of LD. 4) Client/family/carer awareness information needs to be continuously updated and circulated via the hospital teams 5) The liaison nurse needs to work in conjunction with the PALS officer-sharing information and updating services for all.
				32 out of 52 questionnaires were returned from <i>carers/clients</i> . To summarise, 50% used the liaison nurse; 100% found the role useful e.g. in terms of advice, support prior and at the appointment, accessible information etc; 75% felt that contact with the liaison nurse improved their hospital experience e.g. co-ordination of care, clearer explanation of procedures, accessible information, reduced appointment time, obtaining the	

correct treatment, advice and feedback etc; and 100% would use the liaison nurse in the future.	6) The nurse should work in conjunction with other hospitals within the same Trust to look at policies, guidelines and support 7) Essence of Care and benchmarking should be explored 8) Admission and discharge policies should be introduced specifically for patients that are learning disabled. 9) The Hospital Steering Group should continue to develop. Community Care- 1) to continue to develop the role through a rolling training programmes 2) to continue to develop working on a 1:1 basis developing appropriate information for service users and carers regarding their hospital treatment 3) to continue to work jointly with both primary and secondary care settings by sharing and developing new initiatives 4) to continue to produce contact information and circulate throughout the borough to raise the profile of the role 5) develop a benchmarking tool with possible link to Essence of Care team
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6) develop a hospital admission and discharge sheet that can be used borough wide for service users to take into hospital e.g. grab pack, HAP 7) to set up a database of service users within the community who regularly access primary and secondary healthcare services 8) to keep developing links with care managers and hospital social work teams 9) to continue to support people from black and ethnic minorities who also have complex health needs and set up a database of these service users.	
2007 Response to the Death by Indifference report by MENCAP	Sets out the recommendations and actions by Salford on how to improve the care of people with learning disabilities in hospital to avoid incidents like in the Mencap report Salford Royal NHS Foundation Trust Recommendations and Actions 1) adult protection to be incorporated into mandatory training 2) in the event of physical restraint, the carer must be present and the care plan adhered to 3) Information from the patient's own care plan should be incorporated into the nursing care plan, and health action plans should be given to the pwld on discharge 4) PALS have made an accessible leaflet about making a complaint for pwld 5) there is a representation from a pwld and a carer on the Learning

2006	Audit Report- Medway Maritime Hospital Learning Disability Audit	The aim of the audit was to improve the learning disabled patient experience in Medway hospital via assessing staff knowledge and experience, and identifying educational and training needs.	Medway, Kent	Disability Committee 6) Partnership working between the hospital Trust and the community LD team is important 7) Communication leaflets are available in the Matrons Packs on all the wards 8) Carers and PALS advocate on behalf on many patient with learning disabilities 9) outpatients have made it possible for pwld to have longer appointments or appointments at the beginning or end of the day 10) assessment for extra staffing will soon be available 11) an Essence of care group, a nutritional steering group and dysphagia working group are all working towards the nutritional needs of the patients e.g. policies and pwld having red trays to identify that they need assistance.	YES- Conclusions- a collaborative and coordinated approach is needed to review current policies and make reasonable adaptations to become more responsive to the needs of people with learning disabilities and their families.
				The objectives were to develop and distribute an audit tool/questionnaire to a cross section of all employees, and provide an analytical report of findings, including recommendations to improve the patient experience. 417 out of 1130 (37%) of the questionnaires were returned. Communication was highlighted as the greatest problem in affecting the standard of care provided and	

was divided into 5 areas:

- 1) *Patient/clinician communication-* recommendations made for developing toolkits and workbooks for new members of staff and all wards and departments, and ensuring greater awareness of British sign language and Makaton.
- 2) *Clinicians/carer communication-* Recommendations made for a short carers assessment/checklist, carer's guidelines, and audit of carer's opinions of supporting people with LD in hospital.
- 3) *Between Care services-* recommendations made for a Traffic Lights Hospital Care Plan to be available for use, audit of patient and carer's experiences transferring from community services to hospital services and vice versa, for hospital staff to be prepared for the arrival of a patient with LD, and a permanent LD liaison nurse working within the Medway Acute Trust to ensure targets and recommendations for Valuing People are met.
- 4) *Accessible information-* Recommendations made for the Change Picture Bank to be made available to all hospital staff, and for patient information to be coordinated by a multidisciplinary group.
- 5) *Capacity and consent-* Recommendations made for

2006	Report: Learning Disabilities	To provide an outline of the progress of the Trust in regard to the provision of acute care for people with learning disability and their carers.	Sheffield	training for all clinicians. The aim of the project was to review acute service provision of care in the Sheffield hospitals, to identify inconsistencies in care, to establish best practice and to recommend best practice to be implemented. The objectives were to develop 2 separate audit tools; to write standards and carer protocols; to develop a comprehensive pre-admission assessment questionnaire; to develop a ward resource information pack; to recommend staff training; and to develop an integrated care pathway.	Recommendations: 1) The results of the audit revealed that there was a need to assess areas of staff understanding and education e.g. a basic disability awareness training day and a dedicated 2 day workshop. 2) to introduce a learning disability assessment questionnaire for people with learning disabilities and their carers to fill in and bring with them to hospital. To have care standards with regards to elective admission and discharge of patients, and a philosophy of care which underpinned delivery of care. 3) the creation of a nurse consultant or liaison nursing post, to facilitate the implementation of an integrated high quality equitable service and to ensure a more coordinated approach. To have a link person for each acute Trust or within each speciality across the Trust, and to establish a patient and carer focus group to provide an increased ability for them to participate in monitoring and management of their care and provide feedback.
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4) to improve the environment with regards to access, transport, parking and signage.

2006	Audit/presentation	To study hospital staff's experience, their training, the challenges in caring for people with disabilities and the actions that could be taken to improve patient experience.	Medway, Kent	The audit involved an initial literature review, and then hand delivered questionnaires to hospital staff. There was only a 37% response rate. 62% of hospital staff has worked with people with learning disabilities in hospital, 18% of people have received training and 15% were aware of pictorial information on the ward. 80% would like patient held records and computer records and 18% knew who to contact for support. Communication had the greatest effect in patient care and was the biggest training need. The key themes to come out of the focus group relating to people's experiences are: communication, knowledge and understanding, in control and support, and are the same as the themes emerging in existing literature. Implications for practice are discussed e.g. providing accessible information, providing training, planning to help people feel in control and providing practical support (e.g. revising signage and information) and emotional support to patients with learning disabilities	Themes and Reflections: 1) Accessibility> Diversity 2) If their work helps others, they have much to learn from other groups 3) Person centred care as default
2006	Masters- 'Hello, I'm the patient!' The views and experiences of people with learning disability using acute hospital services.	Using focus groups, the aim of the study was to explore the views of people with learning disabilities who have been into general hospital.	North Staffordshire/ Nottingham	NO- The findings of the study resonate with the literature available, but there is a need for further research to follow up on the implementation of suggestions. People with learning disabilities need to be empowered to conduct and present the findings of research themselves.	

2006	Report of a seminar for Health Board Chief Executives: General Hospital Care for People with Learning Disabilities	The aim of this report is to describe a seminar where 3 case studies were presented about people's experiences of hospital care, and presentations were made on resources available (e.g. standards, accessible information); why people with LD are high users of general health services and how to improve hospital care; and good practice examples.	Scotland	to help them understand the process. One of the key recommendations from the presentations is for a learning disability liaison service in all general hospital settings. The good practice examples also include <i>NHS Lothian</i>: There is an acute liaison service whose practice model involves direct patient contact (e.g. clinical advice, interventions, co-ordination, risk management, promoting and modeling and producing personalized accessible information); developing systems (e.g. A&E alert, referral pathways, audit and research); influencing policy (e.g. contributing to the development/implementation of guidelines, policy reviews); and education (all disciplines, grades and departments, internal/external, formal/informal) <i>Fife Primary Care Trust</i>: The LD liaison nurse has developed training for nurses and doctors so that they understand people with learning disabilities and their needs better. Difficulties with training: getting staff released from wards, especially for 2 days, and LD is not a high priority for CPD. Therefore training is now provided at staff induction, statutory training	NO
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with emphasis on communication, and it is hoped to provide 2 hourly afternoon sessions.

NHS Grampian:

Involving carers as trainers in meetings and consultations.

NHS Ayrshire:

Developing electronic patient records to improve access to information.

2006

Report: Meeting the health needs of people with learning disabilities

Royal College of Nursing- Guidance for nursing staff

UK

The report gives guidance on how to define learning disabilities; health needs and services; specific health needs; policy and law; specialist services; supporting access to services; and resources.

NO

2006

Report: Overview of work undertaken. Health Service and Access and Inclusion

To provide an overview of the project and the work carried out.

Manchester

Work completed:

The Pennine Acute Hospitals Trust- Training package developed and delivered to NMGH as an elective course and wider training e.g. NVQ and delivered to professional and non-professional staff with very positive feedback; A& E flagging system looked into but not being used in NMGH systems.
Central Manchester Hospitals- No projects- on hold
South Manchester University Hospitals- Joint Hospital pathway being developed and 2 day event held to raise awareness of LD issues- ongoing.
Accessible leaflets e.g. going into

NO

hospital- ongoing. Audit of planned hospital admission and discharge policy-completed. North Manchester health fair-completed and another is planned in central.					
2006	Report: Audit of MLDP planned hospital admission and discharge guidelines	To gather information on the number of hospital admissions for pwld in Manchester, and to evaluate the use of the MLDP guidelines for good practice for planned hospital admission and discharge for pwld.	Manchester	There were 18 hospital visits made by 13 people. The most common reasons for visits were epilepsy and vein bursts. 11 visits (8 people) resulted in admissions. The MLDP guidelines were used for 3 visits.	Recommendations: 1) Each community team to acquire a copy of the admission and discharge policy of the local acute hospital 2) to review current guidelines and develop a hospital policy 3) MLDP to discuss how to improve monitoring of hospital admissions and recording outcomes 4) to follow up on producing an easy read version of accessible guidelines/policy for pwld. See Masters below
2006	PowerPoint presentation: Understanding the experiences of people with learning disabilities, carers and hospital staff in a Bristol hospital	See Masters below	See Masters below	See Masters below	See Masters below
2005	Masters- Understanding the experiences of people with learning disabilities, carers and hospital staff, in health care provision, at a large inner city general hospital	1) To examine experiences of people with learning disabilities and carers of acute general hospital care 2) to explore the experiences of acute hospital staff of caring for patients with a learning disability 3) to use key stakeholder experiences to recommend	Bristol	Unclear expectations of staff regarding the carer's role in supporting a person with learning disabilities during their hospital stay. Poor communication between staff and carers may explain this. Communication problems are also found in other aspects of hospital care, reflecting a lack of staff knowledge, skill and	Recommendations- <i>Liaison nurse:</i> This study recommends the LD liaison nurse post be re-introduced, on a permanent basis, to help address the above findings. The postholder was found to be highly valued, acting as a catalyst for change.

future approaches to acute hospital care 4) to consider and include people with learning disabilities as participants throughout the research process	confidence in caring for this population. A previous learning disability project nurse post was highly valued, and suggested as being the main catalyst in achieving positive change. A number of pre-admission, admission assessment tools and detailed discharge forms were identified by all groups as being useful. Also accessible information and the learning disability project nurse.	Another recommendation is that key stakeholders become engaged throughout the organisational change process. Also there is a need for a review of the role and support available for family and paid carers, and in making hospital changes there is a need for consultation with pwid.	
2005 Activity report: Learning Disabilities Awareness Training for Hospital Staff	The aim of this report is to describe the learning disability training week which was run by Southampton's community LD team for Southampton hospitals Trust.	Hampshire	YES- To evaluate the training a general evaluation form was used on the day and pre and post training questionnaires were used to assess what learning had occurred. In summary most found the training very useful and could relate it to their practice. Few comments were made regarding improvements that could be made to the training. All participants said that they would recommend this training to others and made additional positive comments. In the post training questionnaires a higher number of respondents reported that symbols were available in their environment, knowledge about learning disability and the LD team had
	The report describes how a project working group was set up to organize a full week of training during learning disability awareness week. The presentations to hospital staff included definitions of learning disability, communication, access issues, consent, physical health needs and role of the learning disability health team. Recommendations: a number of attendees felt the training would be suitable as mandatory training for all hospital staff and a strong view is that LD should also become mandatory within all health professionals initial training,		

improved, as had confidence in working with people with learning disabilities and consent issues were much clearer.

2005	PowerPoint presentation: Pre-admission assessment in secondary healthcare services for people with learning disabilities	This paper explores current evidence base in relation to acute health services, highlights examples of best practice and makes recommendations for future practice and service development. To describe the impact of the patient passport and its function for use in hospital	Hyndburn and Ribble Valley	Highlights initiatives and best practice to improve secondary healthcare for pwld See journal paper Hannon (2005)	NO
2005	PowerPoint presentation: Using a Passport to access acute services for people with a learning disability	To describe the impact of the patient passport and its function for use in hospital	Hull and East Yorkshire	The aim of the passport is to be used to support access between two services i.e. prior to treatment, an outpatient appointment or an admission. It is a snapshot of the person's individual needs at the time and would change as the person's needs change. The passport is now electronic on CDROM.	NO- But the passport has encouraged regular meetings between acute and learning disability staff, raised awareness of LD with acute staff, developed relationships between hospital and LD staff.
2005	PowerPoint presentation: Acute Hospital Liaison Service	To describe the rationale behind and the work of the liaison service	Lothian, Scotland	A pilot project was set up for 1 year and integrated joint trust protocol and development plans were developed. Work by the service included flowcharts to address out patient attendance and patients attending theatre and recovery, highlighting the option to refer or seek advice and support from the learning disability liaison nurse. The purpose of the service was: 1) to optimize actual hospital contact	NO- <i>Project outcomes:</i> 1) patient journeys successfully completed 2) increased flexibility in providing patient-centred care 3) Lothian wide service 4) recognition and value of liaison nursing as 'in-reach' care provision 5) recognised as 'best practice' development 6) Lothian wide service

- 2) co-ordinate treatment
 - 3) provide a person-centred service
 - 4) ensure an inclusive approach to service delivery by acute hospitals
 - 5) provide educational support to healthcare teams
- 7) networking throughout the UK
- 8) raising the profile of patients with LD in the acute services
- Challenges:*
- 1) maintaining a high profile
 - 2) providing educational opportunities
 - 3) reprovision and transition of services
 - 4) GP liaison to enable early referral system
 - 5) developing integrated care pathways
 - 6) research/audit of service
- Key elements to the service:*
- 1) access through 3 way referral route (self/parent/carer, primary care, secondary care)
 - 2) assessment of treatment aims/implications; person's understanding/expectations; admission/discharge implications; environment/logistics
 - 3) producing supportive documentation
 - 4) ensuring quality communication
 - 5) planning and taking re-emptive action
 - 6) developing care pathways
 - 7) maintaining a high profile of the needs of people with learning disabilities
- Reasons for referral:*
- 1) pre-attendance preparation for investigations
 - 2) support during out-patient consultations and investigations
 - 3) assistance with clinical assessment
 - 4) advice on care management
 - 5) discharge planning including arrangements for alternative long term care

2005	Internal report: Learning Difficulties Project Nurse Final Report	The aim of the report is to describe the work of the LD liaison nurse which was a temporary post for 1 year and ended at the end of 2004.	Bristol	6) consent management 7) education Joint working is a key element (steering group, PALS, diversity working group, service audit, utilizing IT systems, education sessions with healthcare staff/supporting agencies/anybody else) The project nurse was developed as a response to Valuing People and aimed to support staff within acute hospitals to meet the health needs of people with learning disabilities. The aims of objectives were: To identify priority areas; identify staff training needs; identify a way of tracking patients with learning difficulties who come into hospital; compile an information and resource pack for staff; identify areas of best practice; identify problems that staff and patients are experiencing and provide guidelines for best practice; establish links with the A&A group; look at the transitional process between Bristol Children's Hospital and the adult services and to identify needs in relation to accessible information . Figures were collated with regards to the patient numbers and	A specialist nurse for LD has now been appointed on a temporary contract for 2 days a week for 1 year from March 2007. Initial goals are reviewed: Training- lunch time seminar and ½ hour awareness raising sessions. Evaluation of the sessions showed that hospital staff found the information very useful and had a better understanding of learning disability issues. There was poor attendance at open sessions and therefore some were cancelled. Therefore it was felt that it would be better use of time for the ward staff to invite the liaison nurse to the ward to undertake a short training session. Resource Pack- The information and resource file
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		conditions. Vignettes and examples of best practice provided by the LD nurse are provided. Aspects of patients' experiences that have highlighted specific areas where practice could be improved are:	for hospital staff has been distributed to all Bristol hospitals and is available on the intranet an internet. The online resource file has been positively evaluated by the Bristol and South Gloucestershire Care Forum.
		1) communication-linked to the communication benchmark of essence of care 2) a communication 'grab' sheet for use by community professionals has been developed to provide the hospital with essential information about the patient. 3) guidelines for best practice are needed when patients are admitted with the support of a paid carer 4) Consent issues-linked to the Trust Consent Policy and Training.	Accessible Information- A patient passport has been developed for patient's with congenital heart defect, as is a patient information leaflet about coming into hospital about the patient's heart. Other accessible information has also been developed for patients and carers.
2005	PowerPoint presentation: Research in Northern Ireland: people with learning disabilities and acute general hospitals	To describe the research to identify the pattern of contact of people with LD in general hospitals; to identify the main reasons for contact; to identify examples of good practice; to describe the challenges encountered by people with LD, families and carers.	"The evidence so far from the Project Nurse Post would seem to support the need for a liaison nurse post within the UBHT hospitals" Challenges encountered in providing equity of access to healthcare: 1) getting some acute hospital managers to realise that this is an issue 2) lack of confidence in and among nurses 3) limited perceived confidence in and among nurses 4) confusion and stereotypes relating to informed consent
		Research: Questionnaires to family and carers of children and adults within WHSB; focus groups with staff within LD services; survey of 100 nurses in acute hospitals. Results: between 2001 and 2003 a minimum of 211 people has contact in 1 of the 3 hospitals in WHSB, and during this time people with LD spent at least 366 days in one of the 3 acute general hospitals.	
		Northern Ireland	

2005	PowerPoint presentation: Transforming St Mary's.	To describe the St Mary's patient pathway project	Westminster, Kensington and Chelsea- London	Examples of good practice: 1) priority system within A&E departments 2) prioritisation on theatre lists to reduce waiting times 3) parents and carers emphasised the importance of skilled communication, confidence in nursing staff, competence of nursing staff, collaborative working and respect for individuals. Transforming St Mary's is a programme of coordinated projects addressing the use of new technology, new roles and new processes, with the aim of improving service efficiency and effectiveness of the Trust, for the benefits of staff and patients. The projects: IT (picture archiving, order communications, electronic discharge communication, choose and book); Roles (redesigning roles e.g. outpatient clinic assistants); Processes (improving the patients' journey (streamlining processes and procedures from pre-assessment to discharge). The patient pathway project outcomes: 1) improved patient experience for pwld and carers 2) decrease the number of inappropriate admissions by increasing the number of people	5) dependence on family and other carers to provide additional support 6) unclear role boundaries and lines of accountability 7) lack of information from learning disability services
				Auditing patient records to see what worked well and what didn't. Consultation: workshops looking at going into hospital, staying at St Mary's, and leaving St Mary's and A&E. <i>Pre-admission</i>- need for training, ensuring people have access to primary care, a re-launch of the communication tool, and ensuring St Mary's can identify pwld and their support needs <i>Inpatient stay</i>- better information when arriving at St Mary's, better training and information on consent and best interest, better information while staying in hospital <i>A&E</i>- better triage in A&E, training <i>Discharge</i>- better communication at discharge	

2005	Agenda Item for partnership board: Acute Hospital Liaison	To discuss the role of the acute hospital nurse	Essex	treated in the community 3) length of hospital stay in line with the general population Discusses the background and issues relating to acute hospital care and pwwd, and sets out the key issues e.g. the access to acute initiatives; introduction of mid-Essex liaison nurse; preparation and planning before hospital consultation or admission; coordination of care at points of attendance, admission and discharge; education within clinical areas and developments of standards of care in hospital. Recommendations: 1) to promote awareness of the liaison role 2) support the development of a liaison nurse for West Essex 3) to ask people about their positive and negative experiences Liaison nurse: the post of LD liaison nurse is commended and acknowledged as a hallmark of best practice. Colchester PCT has 2 of these nurses who contribute to the development of innovative solutions which are improving the care of pwwd in hospital. 2 Nurse specialists are also involved with Essex Rivers NHS Trust and MID Essex Hospitals NHS Trust and provide guidance to hospital staff on the needs of pwwd, and are developing standards of care through the implementation of nationally recognised best practice initiatives, liaising and supporting access, providing assessment, preparation, planning and coordination at all points of admission, attendance and discharge.
2004	Report: Promoting access: The experience of children and adults with learning disabilities and their families/carers who had contact with acute general hospitals in the WHSSB area and the views of nurses in these hospitals.	To describe the research looking at the views of parents/carers, staff within LD services and nurses within acute hospitals.	Western Health and Social Services Board, Londonderry, Northern Ireland.	Main findings: 1) pwwd have regular contact with acute general hospitals in this area; 2) a consistent view across parents and carers was that there are many examples of good practice, but this often represents work by an individual member of staff rather Recommendations: 1) an acute liaison nurse for people with learning disabilities should be appointed within a new full time permanent post to take forward the recommendations of this project and to co-ordinate the

than a consistent approach by all nursing staff; 3) the majority of people had non-emergency contact within the acute hospitals, therefore this provides the opportunity for future planning for this contact in advance. 4) pwld often experience uncertainty, fear and limited involvement in the discussions and decisions, and these difficulties were often related to communication difficulties with the staff and the limited knowledge and skills of the staff. 5) There is a need for additional support for pwld in hospital e.g. from staff in hospital, LD community staff or family, however there was uncertainty about the role of the carers and family. Recommendations: These cover preparation for contact with an acute general hospital, nursing care whilst in hospitals and staff training/research. The success of the project and the recommendations is based upon a committed and co-ordinated approach to their implementation between acute general hospitals primary care and learning disability services.	developments necessary across this area. 2) accessible information should be given to pwld and their carers about what to expect when they come into contact with acute hospitals. 3) pwld who have planned contact with /admission to the acute hospitals should have the opportunity to have a pre-contact assessment of their needs, and a uniform assessment should be introduced across this area. 4) all information should be provided directly to pwld in a format accessible to them 5) further research should be carried out in collaboration with pwld to provide a greater insight into their experience of contact with acute hospitals. 6) extra time should be allocated for outpatient appointments and appointments should be provided early in clinic sessions to minimise the chance of delays 7) current procedures for outpatient appointments requiring examination/treatment, and planned admission for treatment should be reviewed and involve liaison with
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primary, acute and LD staff

- 8) alternative waiting arrangements should be made
- 9) clear procedures that cover planned and unplanned contact of pwld in hospital should be put in place to ensure hospital staff receive information that they require from LD services
- 10) an ongoing programme of education should be put in place for hospital staff e.g. awareness raising exercises and accredited and commissioned short courses
- 11) Trusts should implement the revised protocols on consent to examination, treatment and care and provide training for nursing staff to address these issues with pwld
- 12) the provision of additional support for pwld should be based on a collaborative assessment involving hospital staff and LD services.
- 13) Clarification is needed about the funding for additional support for pwld
- 14) guidelines should be developed on the role the parents/family and LD staff in relation to the support they provide, and should not include delivery basic nursing care
- 15) procedures should also be put in place to ensure support

and supervision is there for the family/LD staff by hospital staff is they are providing additional support e.g. time for meals and rest.
NO

2004	Report: Understanding the patient safety issues for people with learning disabilities	The report outlines the work that the NPSA has done to find out that the patient safety priorities are for pwld	UK	They carried out a literature review; workshops and interviews with pwld and their family and carers; and focus groups with health and social care staff. They found information regarding hospital care : Vulnerability of people with learning disabilities in hospital – 1) communication difficulties makes it harder for pwld to ask for help when they are in pain, ill or need to describe symptoms; 2) lack of training in specific health concerns; 3) additional health conditions such as epilepsy are often not recognised by hospitals; 4) LD staff and carers are often assumed that they are capable of providing full nursing care; 5) the person's LD is likely to affect their ability to understand their illness and treatment; 6) consent being sought from a carer rather than taking time to gain consent from the pwld. Several initiatives are underway to address these issues e.g. health facilitators; health action plans; new roles for LD teams to support mainstream services. The focus groups identified several
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areas of good practice e.g. 'handy hints' cards for hospital staff; health communication passports and LD nurse liaison roles in wards and departments.

2004	Report: of findings from the access to healthcare interviews	To describe the outcomes of the research into learning disabled people's and their carers experience of healthcare	Manchester	Participants talked about experiences in a range of healthcare settings, with a variety of health workers, and for a range of health needs. The key themes identified were: A. Range of health needs, treatments and procedures B. Knowledge about health and treatment – people who are learning disabled C. Feelings about health appointments and services – people who are learning disabled D. Carer and support worker roles E. Health service employee attitudes, knowledge and communication F. Service delivery and organisation	NO-Recommendations Hand held information to take into hospital (possibly in the form of a Health Action Plan). Developing training, information and Technology systems within health services to highlight a person's communication and support needs when they access services. Future research: it would be useful to carry out work looking at people's experience of mental health services.
2004	PowerPoint presentation: Benchmarks for people with learning disabilities using hospital services	To describe the process of benchmarking and what it will mean for pwld	Teeside/North East Yorkshire, Hartlepool	10 new benchmarks to add to existing ones: access to hospital, specialist skills and knowledge, attitudes and behaviour, support (patient and carer), information about patients, communication, awareness raising, risk assessment and management, activity, and coordination of care and discharge planning. The process: all area to use the	NO

2004	Powerpoint presentation: Access All Areas	UK	To describe a project by the Department of Health to improve patient experience by providing fast, fair, convenient high quality services which respond to people's needs	tools (real and theoretical), comparison group, tool amended and work started, re-distribute to all areas to be used with all other benchmarks- work ongoing. Involving pwid and family carers; Health action plans and facilitation; Working together 9service users, family carers, primary care, acute care, specialist LD services, social services etc); Mainstream developments (e.g. NSF's, Essence of care, NHS Direct, Walk in centres); The project was a response to critical incidents involving in-patient care and started with the development of a working group. The project aimed to capture the patient and carer experience and involved developing pathways and protocols.	NO	Improving practice: 1) developing a pictorial journey around department 2) common procedures in accessible format on intranet 3) discovery interviews 4) offering people with LD the 1st appointment 5) pictorial file of ward staff 6) developing an integrated care pathway for epilepsy 7) photographic menus 8) supporting carers through volunteers Extremely positive feedback and evaluation from the training.
2004	PowerPoint presentation: Care Beyond Words. Sharing the Sheffield Experience	Sheffield	To describe the work of the Access to Acute Care Project	Positive outcomes: 1) LD steering committee 2) PALS involvement 3) having a 'champion' 4) links with wards and departments 5) local and national profile 6) increased awareness of the specific care issues, health inequalities and difficulties accessing mainstream healthcare. Training- 2 day programme: Day 1-Included an overview of the project, policy, current trends,		

2003	Report: Liaison nurse for patients with a learning disability	To describe a 6 month pilot project to see whether the liaison nurse is a valuable much-needed role.	Barnet	communication and consent, action planning and case study Day 2- included contributions by MENCAP, Down's Syndrome Association etc and action plans The project was set up as a result of a complaint made by the relative of a patient whose needs were not addressed in hospital. A liaison nurse role was piloted for 6 months, working 1 day a week at the hospital. She made herself known to the wards and the A&E department. She also liaised with the Matron for Medicine and a referral system was set up. A questionnaire was used at the end of the 6 months to see if the role had been beneficial and what the training needs of the hospital staff were.	YES- Although the role was only for 6 months and 1 day a week, the post showed immediate benefits: <i>Benefits for hospital staff:</i> Resource point; advice on treatment; improved communication and understanding between the hospital and the community homes; improved communication with the LD consultant ; raise the profile of LD and make staff more aware of their specialised needs; education; knowledge and confidence building; reduction of aggressive and inappropriate behaviour from patients. <i>Benefits for the patients:</i> Patient advocate representing their needs and rights; more appropriate treatment in a timely manner; specialist needs acknowledged and support given; link between hospital and the community; prepare the patient for hospital planned admission resulting in a more
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co-operative and compliant patient, with shorter length of stay; relatives able to access and discuss.

Benefits for the Community Trust:

Communication link for the hospital to the community homes, making them more aware of the problems that may occur when a person with a learning disability is admitted as an emergency so that the home can support the patient as much as possible whilst in hospital.

Future Development:

- 1) Proposal put forward for a substantive post to carry forward and develop the post
- 2) Develop preparation sessions for patients booked for elective surgery to reduce anxiety and non-compliance
- 3) Audit the service again after 6 months

(In September 2006 the PCT finally funded a full time LD Liaison nurse to be based in the hospital, based on the initial pilot from 2003.)

NO

2003	Report: promoting health-supporting Inclusion. Healthy Lives, Part of the Community.	Reports on how nurses and midwives can support children and adults with learning	NHS Scotland	The report states that pwld need information on how to keep healthy; need to be able to access the
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disabilities and their families

services that they need; and to be treated as an individual and with dignity.

As a result of the report it is expected that:

- 1) pwld will get regular checks
- 2) be able to see a local doctor or nurse
- 3) local surgeries or health centres should have nurses who are specially trained in the needs of pwld
- 4) there will nurses whose job it is co-ordinate support for people who have to go into hospital
- 5) people with complex needs should have a named children's or learning disability nurse to co-ordinate their care
- 6) Information about people's health need's will be put into their personal life plans.

2003	Report: DH Consultation on choice: Fair for All and Personal To You.	This report is a response from North West Hospitals and Learning Disability Network, to provide recommendations in relation to Emergency Care and Planned (Elective) Care.	North West	Recommendations: <i>Emergency Care:</i> awareness raising opportunities for staff in A&E in relation to communication and pwld; awareness of individual right and Disability Discrimination Act; understanding of consent issues in relation to pwld; local information about how to contact carers and LD services; establishment of 'on site' LD liaison nurses within general hospitals; availability of simple aids and equipment in emergency services (e.g. pictures of body parts);
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establishment of appropriate protocols between agencies supporting pwld; the development of personal health records; support and partnership working with LD staff supporting medical staff; support for NHD direct staff from LD staff; establishment of core standards and training and development opportunities; awareness raising across emergency admission departments; an understanding of the behaviours that pwld may display; support with choices in healthcare for staff such as reception and triage nurses; identification of a LD on admission could assist NHS staff to work more effectively.

Planned Care: work in primary health care to identify health needs to increase the chance of planned care rather than emergency care; improvement in the quality of information to hospital staff from GP's and LD teams; the establishment of 'protected admissions' for vulnerable people; introduction of 'dependency assessment tools' may assist individuals and NHS staff to have the right level of support; admission planning including the involvement of care managers and practitioners; introduction of appropriate

signposting in hospital corridors; joint funding between health and social services departments to increase levels of support for individuals; PALS officers need development opportunities to assist them in their work to increase choice with pwld; partnership working between hospital teams, social services and other agencies; work with the District nursing teams regarding the particular needs of pwld; work needs to be undertaken with hospital staff to ensure that such incidents as people being catheterized or having PEG feeds are avoided just to 'make nursing care easier'.

2003	PowerPoint presentation: Learning Together Improving Access to Services- Barnet's Story	To describe the work of the joint project between the hospital and the community	Barnet	NO
Aim: Improving communication through working groups; pulling together the needs of the community and combining the needs of the hospital; and producing a draft hospital book and guidelines. Emphasis on collaborative working for consultation and presentations; piloting the hospital book; recruiting link nurses and therapists. Outcomes: Link nurses on every ward; launch day-resource packs containing guidelines, hospital book, pictures and other helpful literature, commitment from both Trusts and community training programme				

2003	PowerPoint presentation: Access to Acute Hospital Services	Training- To provide background information about the issues of acute care for people with learning disabilities and to describe the 'Let's be Patient' video	Shropshire	THEREFORE: links are now established, teaching sessions in community and hospital are now available; complex surgical cases are managed better; day surgery has robust system; continuing work as necessary. Describes the essence of care benchmarking and examples of good practice; looks at the hospital admission personal information sheet;	NO
2003	Role of health access nurse (responsible for both primary and secondary care)	To set out the objectives of the health access nurse	Shropshire	Level 1: Access to acute by liaising with the PALS service (regular meetings, developing accessible information, re-establishing the Grab Sheet, accessible communication cards, improve communication via GP to acute and service users, webpage.	NO
2002	Report: Access to (Secondary) Care. Supporting people with a learning disability on admission to hospital	The aims of the project are to examine the issues surrounding access to acute hospital care by pwld; to make recommendations as per the guidance within 'Valuing People'; to identify areas of best practice; and to produce a resource pack that could be used across the West Midlands	Shropshire (Access to acute network)	Recommendations: 1) Strategy (e.g. auditing numbers of pwld accessing hospitals; essence of care benchmarking; hospital philosophy) 2) training (e.g. awareness training for hospital staff; hospital LD liaison nurses appointed to assist with the assessment, planning , evaluation of nursing care for pwld and ensuring a coordinated approach both in the hospital and with the community settings 3) Communication (e.g. developing patient passports/client records, user friendly accessible	NO

2002	Proposal for funding for a learning disability liaison nurse	To describe the proposal for a liaison nurse to work in acute general hospitals	Argyll & Clyde, Scotland	information) 4) Clinical management 5) Carers (e.g. provision of a relatives room, additional support for carers) 6) Liaison (e.g. PALS service to promote improved hospital services) 7) Management (e.g. minimal waiting times in out patients, quiet waiting areas) 8) Environment The context behind the issues are discussed, including the recommendations from the 'Promoting health, supporting inclusion' document e.g. the development of a protocol and training for staff, and the development of a learning disability liaison nursing service within acute general hospitals. Examples of good practice are also put forward e.g. a LD dependency assessment scale (Lothian & Sheffield), a collaborative protocol for care (Lothian & Sheffield), Patient and carer questionnaires (Sheffield), GP referral forms (Sheffield) and training plans (Sheffield). The objectives of the post would be: coordination of care, education within clinical areas, support and advice, collaboration between agencies, development and	NO	After 6 months activity would be reviewed along with an annual formal appraisal. A full evaluation would take place at the end of the 2 year period, including workload analysis (referral, reviews, training). Achievement of protocol objectives (audit of standard questionnaire to professionals and users.
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enhancements of care standards, development of audit mechanisms, promotion of effective communication and support for family/carers. The post would be for 2 years initially with formal evaluation.

2001	Report: The Learning Disability Care Pathway Project	To describe the Action research project, which piloted a care pathway approach to acute care for people with learning disabilities, to see if it improved the quality of their experiences in Burnley General Hospital.	Collaboration between Burnley Health Care Trust's LD nursing service and Burnley general hospital	Based on the Lothian project in Scotland, Burnley health care trust adapted and implemented their own care pathway, which involved tasks such as a referral system to the care pathway facilitator, assisting with pre-admission assessments, assessing dependency levels, participating in discharge planning, providing accessible information etc. Prior to implementation, a baseline audit of 13 patients was carried out. After 6 months, a process review took place, with another case note audit and review and questionnaires circulated to patients, carers, and general nursing staff. 8/18 patients, 12/21 carers and 24/40 nursing staff returned the questionnaires.	YES- <i>Care pathway outcome-</i> Although the care pathway had been commenced in most cases, not one had been fully completed, and the assessment of dependency had only been used 3 times. <i>Case note review-</i> Needs were being assessed, even if not by the dependency scale. Specialist LD nursing support has been accessed by some hospital staff. <i>Questionnaires-</i> Generally the information available in hospital was not adequate to meet the needs of patients who rely on more than the written word. <i>Recommendations-</i> Based on the research project, the researchers recommended the appointment of a full time LD liaison nurse to: 1) improve communication (e.g. signposting systems and
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				2) liaison with the facilitator had taken place regarding admission issues and practices, 3) partnership working was prevalent through out the project, 4) clients and carers were involved in discharge planning and 5) further assessment had been requested. accessible information), 2) facilitate training (provide training for all staff in the hospital e.g. receptionists, porters, registered nurses, health care assistants), 3) provide assessment (by piloting the LD initial screening tool to all points of entry to services), 4) provide direct input to clients, relatives/carers, 5) working with the primary care and community services (e.g. develop a 'trigger' system so that the liaison nurse is alerted once a referral to hospital has been made by the GP), 6) working in partnership with acute sector staff (e.g. accepting referrals, participating in discharge planning, interventions for consent issues etc), 7) working with the LD care pathway project group.
2001	Overview of a project: Improving patient access and communications systems for people with learning disabilities accessing acute and community hospital services	To provide a brief overview of the project and the outcomes	Barnet	The project was set up 1999 and a hospital steering group identified 4 key objectives: 1) to raise awareness of the health needs of people with LD when accessing mainstream NHS services 2) to develop and produce communication resources 3) to identify training needs of health professionals working in Benefits of the project: 1) Having a multi-agency membership that shared ideas, developments and partnerships at the start enabled involvement by all, and led to the development of resources, training and good practice guidelines. 2) The project received full

			acute hospital to pilot training programme 4) to develop hospital guidelines based on good practice 3 forums were set up: a multi-agency steering group, a hospital nurses working group and a self-advocacy health information group. Several documents were produced from the project : 1) a hospital book (providing personal information and a picture communication resource for people) 2) training package (for health professionals on consent and communication 3) communication directory (for health professionals) 4) hospital guidelines (for people with learning disabilities based on good practice).	commitment from senior nurses and managers within 2 NHS Trusts and the health authority. 3) 45 designated health professionals working across NHS hospitals were identified to carry the project forward e.g. training colleagues. 4) The project benefited other people e.g. those with communication problems such as stroke patients, older people and those with English as a second language.
2000	Report: Secondary healthcare for people with a learning disability.	A report completed for the Department of Health to analyse the strengths and weaknesses of the current provision of secondary healthcare for pwid in England, to identify good practice, and to develop guidance to facilitate the development of good practice in this field throughout the NHS.	Four NHS regional offices (London, Northern and Yorkshire, Trent and West Midlands)	NO
			Data collection involved 2 conferences in Sheffield and London, and a workshop at the Royal Shrewsbury Hospital. <i>Hospital experiences results:</i> 1) poor communication (e.g. limited skills of staff, inadequate information about procedures, discharge, choices) 2) fear and distress 3) poor quality of care <i>Carer experiences</i> <i>Hospitals</i> (poor information on admission, limited staff training, risk	

to other patients, consent issues)

Main solutions proposed:

- 1) Improves information (e.g. patient held data; preparation for admission; training programmes)
- 2) More effective support arrangements (e.g. more collaborative working with family carers; specialist support teams)
- 3) Improving the quality of care (e.g. improving the hospital environment, access to expertise, the development of new specialist services)

1997	Abstract/Questionnaires- Meeting the needs of people with learning disabilities in hospital.	A project group was set up to consider the extent of the problem in hospitals meeting the needs of people with learning disabilities, and to suggest local solutions.	Salford: University of Salford, Salford Community Health Care Trust and Salford Royal Hospitals Trust	100 questionnaires were distributed to staff on A&E and orthopaedics, and 45 were returned. Analysis of the questionnaires indicated that staff had widely varied ideas about the nature of learning disabilities, but 30 expressed a wish for further training (in areas such as effective communication, behaviour, care in the community, different types of needs, assessments and resources). The project team wanted to develop 2 or 3 day workshops for staff to meet these needs, however, they were only able to organise 2 hour workshops to enable participants to discuss their own experiences and explore issues relating to their attitudes.	NO- Evaluation of the workshops was planned but not carried out.
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Appendix 2: National resources and tools to Improve Access to Acute Hospitals for people who are learning disabled

Area/Service	Type of document	Aims	Content
Access to secondary care report appendix (Shropshire 2002)	Good practice examples that the original report identified	To provide examples from the West Midlands and across the UK	Provides examples of 1) liaison nurse models, 2) Information (e.g. guidelines, hospital books, patient passports), 4) users (e.g. pwld being involved in making videos etc), 5) training, 6) carers, 7) preparation for surgery 8) benchmarking
Access to secondary care report appendix (Shropshire 2002)	Essence of care benchmarks for people with learning disabilities	To provide acute hospital care for patients with learning disabilities: patient focused benchmarks. The outcome is that all people accessing hospital services will receive appropriate, individualised, quality care.	10 extra benchmarks on: 1) information to access hospital, 2) specialist knowledge and skills, 3) attitudes and behaviours, 4) support, 5) Information, 6) communication, 7) awareness raising, 8) equipment, 9) balancing observation and privacy in a safe environment, 10) activity.
Access to secondary care report appendix (Shropshire 2002)	Guidance	Disabling Practice- and how to avoid it. Providing equal access for disabled patients in the NHS	Provides brief guidance on talking, facilitating, listening, supporting,
Barnet Healthcare	Personal Information sheet for people with learning disabilities	This tool is intended to be filled out prior to a hospital visit/admission by the pwld and/or their carer, to help hospital staff to know more about the patient	Included information such as patient details, personal needs (e.g. communication equipment needed), medical Information, medical tests etc.
Bristol Healthcare NHS Trust	Information and resource file for hospital staff	This tool is intended to be used as an information resource for hospital staff to provide information about people with learning difficulties	Covers issues such as the difference between a learning difficulty and a learning disability; how you might identify someone with a learning difficulty; gathering information on hospital admission; carers; communication; consent; difficulties which might affect a person's stay; discharge and PALS.
Camden PCT	Traffic light hospital booklet	This tool is intended to be filled out prior to a hospital	Split into 3 sections: Red (things you must know about me e.g. patient details, GP, medical history, medication),

Gloucestershire Partnership NHS Trust	Traffic Light Hospital assessment	visit/admission by the pw/d and/or their carer, to help hospital staff to know more about the patient This tool is intended to be filled out prior to a hospital visit/admission by the pw/d and/or their carer, to help hospital staff to know more about the patient Guidance for hospital staff on supporting pw/d	Orange (things that are important to me (e.g. communication, understanding, level of support, seeing and hearing, mobility, food and drink support etc), Green (things I like and things I don't like) Split into 3 sections: Red (things you must know about me e.g. patient details, GP, medical history, medication), Orange (things that are important to me (e.g. communication, understanding, level of support, seeing and hearing, mobility, food and drink support etc), Green (things I like and things I don't like) Covers issues such as learning disability definitions, questions to ask yourself if you think a patient has a learning disability, guidelines on communication, explanation, reducing anxiety and consent, Provides information about the choose and book system e.g. choosing a hospital, telephoning to make an appointment etc. This sheet is to be accompanied by current medication and medication record sheet, and covers information such as patient details, medical history, special considerations, daily living skills, behaviour etc
Gloucestershire Partnership NHS Trust	Handy Hints Information card	To help people with learning disabilities to arrange health appointments This tool is intended to be filled out prior to a hospital visit/admission by the pw/d and/or their carer, to help hospital staff to know more about the patient	Covers areas such as patient details, likes and dislikes, medication, allergies, and things the patient needs help with.
Hambleton and Richmond PCT	Accessible Choose and Book leaflet		
Heywood & Middleton and Bury PCT	Hospital Admission Information Sheet		
Hull and East Yorkshire Hospitals NHS Trust	Patient Passport		
Lothian University Hospitals Trust/ Lothian PCT	Protocol/Policy/guidelines- A collaborative approach to caring for patients with a learning disability in the acute hospital	To assist hospital staff in the care of a patient with learning disabilities. The aims are: to enable the wards to audit their delivery of care standards against the Essence of care guidelines; to enhance communication between the patient, carers and health care	Includes flow charts (for the core principles of patient care; elective admissions; emergency admissions; out-patient attendance; patients attending theatre and recovery); role of the learning disability liaison nurse; out-patient attendance; care of patients attending theatre and recovery; emergency admission; duration of hospitalisation; and consent and advocacy

Luton and Dunstable NHS Trust	All About Me information booklet	professionals; to ensure a high standard of care is provided throughout the patient's journey; to highlight issues of consent and advocacy for pwld; to identify the learning disability liaison nurse role as a resource for the acute Trust in relation to assessment of need, planning of an individual's care requirements, education and support; and to promote the use of the learning disability assessments scale in order to identify the additional care needs and resources that may be required to support the patient. This tool is intended to be filled out prior to a hospital visit/admission by the pwld and/or their carer, to help hospital staff to know more about the patient.	Covers areas such as communication, current medical conditions, pain, medication, anxieties and fears, personal care, continence, eating and drinking, mobility, keeping safe, and interests
North Staffordshire Hospitals NHS Trust and North Staffordshire Combined Healthcare NHS Trust	Guidelines for A&E staff when treating people with learning disabilities	To assist hospital staff in providing a complete service for pwld. The guidelines should be used in conjunction with attendance at the teaching session provided by the PCT	Covers issues such as telephone communication, triage, fact tracking, waiting and use of a communication information leaflet
Royal Free Hampstead/ Camden	Going into hospital booklet	An easy read accessible document to help the pwld to understand about going into hospital	Covers issues such as what I need to know before I go into hospital, what the hospital needs to know, what I need to take with me, when I arrive at hospital, what I can do in hospital and when I leave hospital
Scottish Consortium for learning disability	Postcard- Top Tips for health professionals from people with learning disabilities and family carers	Brief tips/guidelines for health staff on how to work with pwld	Covers issues such as communication, appointments, and training.
Sheffield	Patient assessment	This tool is intended to be filled	Covers areas such as patient details, safety, communication,

	questionnaire	out prior to a hospital visit/admission by the pwld and/or their carer, to help hospital staff to know more about the patient	breathing, eating and drinking, using the toilet, washing and dressing, mobility, sleep, sexuality, mental health, working and recreation, and carer's details
Sheffield	Pre-admission assessment guide	To assist hospital staff on the procedures for elective and emergency hospital visits for people with learning disabilities	Flow chart showing the procedures for elective and emergency admissions.
Sheffield	Care guidelines/ Care Protocols/ Standards of Care/	To assist hospital staff in the care of a patient with learning disabilities	Covers issues such as planning an admission, the planned admission, emergency admission, patient discharge, outpatient appointments,
Shropshire County PCT	Hospital leaflet: Your next patient has a learning disability...	A practical guide for health care professionals to effectively meet the needs of patients with a learning disability	Covers information such as what is a learning disability, the healthcare visit, techniques to use with pwld, consent, and tips re: waiting, carers.
Surrey LD partnership Board	The Hospital Communication Book	To give acute hospital staff basic information about the communication needs people may have, and to be a practical communication tool that people can use to communicate together	Covers areas such as communicating clearly with speech, supporting people with visual impairments, supporting people with a hearing loss, using signing to support speech, using photos, pictures and symbols,
Unknown	Coming into hospital questionnaire for people with learning disabilities	Questionnaire to get the views of pwld about their experience of going into hospital	Asks questions about people's feelings about going into hospital, the hospital staff, the ward, going home etc.

North West regional resources and tools to Improve Access to Acute Hospitals for people who are learning disabled

Area/Service	Type of document	Aims	Content
Blackburn and Ribbles Valley PCT/ Healthcare Trust	Pre-admission assessment	This tool is intended to be filled out prior to a hospital visit/admission by the pwld and/or their carer, to help hospital staff to know more about the patient	Includes vital information about the patient and also a dependency assessment section where the person is rated on how much support they require in areas such as communication, skills, eating and drinking, continence, mobility, medication, sleep pattern, behaviour etc
Burnley Health Care NHS Trust	Care pathway indicator/screening tool	The tool is intended to assist staff in identifying people who may have a learning disability- for use by the triage nurse. An easy read accessible document to help the pwld to understand about going into hospital	Questions on temporal orientation (date, time year etc) and spatial orientation (where did accident happen, how did you get to hospital etc), and contact numbers for the care pathway facilitator. Covers issues such as who you will meet, what to bring with you, what not to bring, shopping in hospital and going home.
Countess of Chester Hospital NHS Foundation Trust	Inpatient Information booklet	To provide the hospital with information about the patient	Covers communication, support needs, special needs etc
Crewe	Pre-op assessment/ Screening tool	This tool is intended to be filled out prior to a hospital visit/admission by the pwld and/or their carer, to help hospital staff to know more about the patient	Includes vital information about the patient and also a dependency assessment section where the person is rated on how much support they require in areas such as communication, skills, eating and drinking, continence, mobility, medication, sleep pattern, behaviour etc
East Lancashire PCT/Hospitals Trust	Pre-admission assessment	This tool is intended to be filled out prior to a hospital visit/admission by the pwld and/or their carer, to help hospital staff to know more about the patient	Includes vital information about the patient and also a dependency assessment section where the person is rated on how much support they require in areas such as communication, skills, eating and drinking, continence, mobility, medication, sleep pattern, behaviour etc
Heywood & Middleton and Bury PCT	Hospital Admission Information Sheet	This tool is intended to be filled out prior to a hospital visit/admission by the pwld and/or their carer, to help hospital staff to know more about the patient	This sheet is to be accompanied by current medication and medication record sheet, and covers information such as patient details, medical history, special considerations, daily living skills, behaviour etc

Lancashire Teaching Hospitals NHS Foundation Trust/Central Lancashire PCT	Traffic Light Hospital Information	This tool is intended to be filled out prior to a hospital visit/admission by the pwld and/or their carer, to help hospital staff to know more about the patient	Split into 3 sections: Red (things you must know about me e.g. patient details, GP, medical history, medication), Orange (things that are important to me (e.g. communication, understanding, level of support, seeing and hearing, mobility, food and drink support etc), Green (things I like and things I don't like)
Oldham PCT	Traffic Light Hospital assessment	This tool is intended to be filled out prior to a hospital visit/admission by the pwld and/or their carer, to help hospital staff to know more about the patient	Split into 3 sections: Red (things you must know about me e.g. patient details, GP, medical history, medication), Orange (things that are important to me (e.g. communication, understanding, level of support, seeing and hearing, mobility, food and drink support etc), Green (things I like and things I don't like)
Pennine Acute Trust	Personal Information card/Risk assessment for person with special/additional needs	To be filled in by hospital staff with the help of the patient and/or carer	Covers information such as level of learning disability, carers, staff support, communication skills, main anxieties, medication, waiting issues, consent etc.
Stockport NHS Trust	Information sheet for hospital staff	Tells hospital staff about the levels of co-operation for investigations and treatment for people with a learning disability	Covers areas such as level of explanation required, expression of pain, medication, blood pressure monitoring, temperature, injections, bloods being taken, I.V infusions, ECG, EEG etc
Tameside LD service	Profile for hospital admissions/ admissions and discharge sheet	This tool is intended to be filled out prior to a hospital visit/admission by the pwld and/or their carer, to help hospital staff to know more about the patient	Covers areas such as patient details, communication, current medical conditions, medication, mobility, sensory issues, self-help and personal hygiene, and behaviours.

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