

Patient Advice and Liaison Service  
Draft Report on access to acute secondary care for patients with learning disabilities

South Manchester University Hospitals   
NHS Trust

**REPORT OF THE SOUTH MANCHESTER UNIVERSITY HOSPITALS TRUST**  
**PALS SERVICE ON ACCESS TO ACUTE CARE FOR PATIENTS WITH**  
**LEARNING DISABILITIES**

**Elaine Clark**

**Patient Advice and Liaison Service (PALS)**

**And**

**Manchester Learning Disability Partnership (MLDP)**

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**Report of the South Manchester University Hospitals Trust PALS service on access  
to acute care for patients with learning disabilities**

**1. Introduction**

**1.1 Origin of report**

This report has been compiled as part of work conducted by the Patient Advice and Liaison Service in recognition of the difficulties highlighted by patients with learning disabilities when trying to access acute health care.

The report aims to:

1. Summarise the concerns raised by this patient group and their carers.
2. Develop recommendations for action to improve access to secondary health care and to capitalise upon the good practice identified within South Manchester for this patient group.

**1.2. Why is this area of healthcare relevant and important?**

Although people with learning disabilities represent a relative minority of the patient population of South Manchester;

1. People with learning disabilities represent a patient group which regularly and increasingly contacts the PALS service for help and support.
2. People with learning disabilities are known to have much greater health needs than the general population (Signposts for Success. ~Department of Health 1998, Lindsey 1998) with a much greater risk of sensory impairments, mental health problems, epilepsy, cerebral palsy and other physical disabilities.
3. People with learning disabilities are living longer and many children with very severe health problems are now surviving into adult life.
4. People with learning disabilities are therefore likely to be frequent visitors to an acute trust and to have much higher incidence of admission than the general public.  
**"26% of people with a learning disability are admitted to general hospitals every year, compared to 14% of the general population"** (Mencap, The NHS Health for all, 1995)
5. Most of the complaints received by Mencap are about treatment of people with learning disabilities by **doctors and hospital services.**

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6. The principles of the Government White Paper, Valuing People (Department of Health 2001) are principles which apply to all patients; principles of rights, independence, choice and inclusion. It follows therefore that if "you can get services right for people with learning disabilities, then you can be sure that they will be OK for everyone else".  
Department of Health 1998

The stated aim within Valuing People (2001) is:

**"To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary."**

This aim expresses the desire of all patients, whether with learning disabilities or not.

7. "People with learning disabilities have the same rights of access to NHS services as anyone else.." and equity of access should never be in dispute. (Department of Health 1998)
8. Steps to improve access to healthcare for patients with learning disabilities will fit in with the wider government initiative to reduce health inequalities, with work around the National Service Frameworks, Care Standards and the agenda of the National Patient Safety Agency.

People with learning disabilities have the right to the same level of medical and nursing care as that provided to the general population. This care must be flexible and responsive and any diagnosis or treatment must take into account any specific needs generated by their learning disability.

## **2.Summary of evidence and policy in this area**

There is now a considerable body of evidence which demonstrates that people with learning disabilities have higher levels of health needs than the general population. Evidence also suggests that people with learning disabilities experience significant barriers in accessing this health care, resulting in disorders which are undiagnosed and untreated. However, less attention has been focussed upon the experience of people with a learning disability within secondary healthcare Cumella and Martin (DoH 2000).

**2: 1 *Atkinson and Scarloff (1984)*** highlighted:

1. Lack of awareness amongst nurses of special needs of disabled people
2. Difficulties experienced by patients in communicating needs/pain, leading to
  - a. difficulties in continuing smooth interactions with nursing staff
  - b. to this I would add, difficulties in diagnosis and treatment
3. Anticipation of increase in disabilities following admittance eg. pressure sores
4. Nurses identified lack of training leading to uncertainty when communicating with disabled people.

**2:2 *Building expectations (1995)***

A stay in hospital "can be a very frightening experience": recommended better information in accessible formats.

**2:3 *Signposts to success (1999)*** recommended:

1. Training of staff by patients
2. Introductory visits
3. Videos of the hospital
4. Guidance around consent

**2:4 *Valuing People (2001)***

"Mainstream secondary health services must also be accessible for people with learning disabilities. There must be no discrimination. Support will be needed to help people with learning disabilities admitted to a general hospital for medical or surgical treatment to help them to understand and co-operate in their treatment."

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Highlighted importance of helping people with learning disabilities to access healthcare as part of wider government initiative to reduce health inequalities. Also highlighted difficulties around consent for this client group:

"The government is committed to having good consent to treatment practice in place in all health settings. This is of particular importance in general hospitals where staff may be unfamiliar with seeking consent from people who have learning disabilities."

Valuing People also saw PALS as having a "especially important role for ensuring that people with learning disabilities can access full range of NHS provision". p65

**2:5 *The NHS, Health for All*, (Mencap 1995) and *Treat me Right* (Mencap: 2004)**

Investigation into healthcare of people with learning disabilities "**..shows that urgent action is needed to improve the health of people with a learning disability....Professionals in all healthcare sectors need to show that they can do things better and rise to the challenge of improving the health of people with a learning disability.**"

The Mencap report claims that the history of medical care of people with a learning disability within long term hospitals has meant that they have become isolated from mainstream health services, whilst in turn the mainstream sector has lacked the opportunity to develop skills in the diagnosis and treatment of this patient group. The report goes on to describe a prevalence of "diagnostic overshadowing" which has also been documented by the National Patient Safety agency. The British Journal of Psychiatry describe this as "..dismissing changes in behaviour, personality or ability that would be taken very seriously in a person without a learning disability." 176 pp26-31

The Mencap report (2004) also highlights neglect which can occur when patients are unable to tell staff what they need or that they are experiencing pain. It describes particular problems around feeding and drinking with nutritional needs of patients with learning disabilities being unmet and it highlights low expectations which can result in bedsores and other conditions not being managed.

In this report there is mention of discrimination, either as a lack of understanding and training in this area or involving value judgments about the worth of a person with learning disabilities. It gives as an example of this the allegations made in 2001 against the Royal Brompton and Harefield hospital for refusing heart surgery to children with Downs syndrome.

Mencap recommends:

1. Better training in learning disabilities for all healthcare staff.
2. Longer and more flexible appointments

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3. Provision of accessible information.
4. Identification of a learning disability on health records.
5. Appropriate levels of support to be provided by hospitals in order to enable them to fulfil their legal duty of care.

**2:6 *Equal treatment: Closing the Gap 2005***

The Disability Rights Commission is currently conducting an enquiry into health inequalities faced by people with long term mental health problems and learning disabilities "**because of the overwhelming weight of evidence pointing to disparities in health outcomes**".

**2:7 *PALS***

Valuing People describes PALS as having an "especially important role (in) ensuring that people with learning disabilities can access full range of NHS provision". p65

Amongst the core standards for PALS are :

- To be proactive in working with patients at risk of exclusion
- To facilitate patient centred care
- To amplify the voice of those in danger of not being heard
- To work across boundaries

Therefore PALS has a natural gravitas towards patients with learning disabilities.

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**3.Methodology**

The evidence for this report has been gathered from the following:

1. Issues relating to patients with learning disabilities brought to PALS
2. Incidences highlighted through the Hospital Incidents Reporting System (HIRS)
3. A "user day" at Manchester People First in which people with learning disabilities and their carers from across the City and surrounding area spoke with PALS about their experience in South Manchester University Hospitals Trust. This was attended by 40 people with learning disabilities.
4. Interactive session with clinical staff on "consent for patients with learning disabilities" training days.
5. A conference held in South Manchester University Hospitals Trust, attended by staff from the Trust and other Trusts across Manchester, people with learning disabilities and carers. This conference was utilised to draw up actions for improving acute hospital care for this patient group. This also included staff from other hospitals within Manchester in order to draw up plans for across the city. This was attended by 107 people and was arranged by Manchester People First with support from PALS.
6. Specific focus days at Manchester People First utilising drama to explore the subjects of consent and of the new Choice programme. These days were utilised to work with people with learning disabilities to identify ways to improve their experience around consent and to identify information needs of this client group for the new Choose and Book programme.
7. Interviews with staff from community learning disability services
8. Interviews with unpaid carers of patients with learning disabilities.
9. Specific issues highlighted by Manchester Learning Disability Partnership.

**Summary of methodology**

<b>Methodology</b>	<b>Number of participants</b>
Concerns raised through PALS	79
HIRS reports highlighted to PALS	05
User Day	40
Staff consent training	
Health conference	107
Focus day	25
Meetings with staff from MLDP	12
Interviews with carers	04
Issues highlighted through learning disability partnership MLDP	15
<b>TOTAL</b>	<b>287</b>

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**3. Findings**

The above methodology included detailed accounts of the experiences of people with a learning disability, both as in-patients, as out-patients and in A & E. The overriding experience was of feeling, "ignored, uncomfortable, nervous, scared, confused, ignored, lonely, uncared for, without choice or understanding." There were also some instances of more positive experience, highlighted through PALS, especially in the area of surgery (F3), (A5) and clinical support (radiology). In these areas several excellent staff had gone out of their way to improve the patient experience for patients with learning disabilities. However, overall the key areas of concern can be summarised as follows:

**4.1 Communication**

Communication difficulties emerged as a major theme through all areas of methodology.

In particular,

➤ *Lack of confidence in and resources for staff in communicating with this patient group*

Fear amongst staff in communicating with people with a learning disability. Staff revealed that they were unfamiliar and embarrassed when communicating with patients with learning disabilities. Many staff mentioned that they were fearful of appearing insulting or condescending and that this created barriers in communicating with this patient group.

Nursing staff spoke of lacking confidence in their ability to communicate with and treat this client group. Obtaining informed consent was recognised as a particular area of difficulty.

Staff also spoke of the pressures from lack of time when working with people with learning disabilities, people who it has been recognised require up to four times longer than the general population for successful communication and consultation.

Patients spoke of staff not speaking directly to them, of a lack of explanation for their admission or treatment and of an absence of attempts to determine the extent to which patients understood or could give consent. Overall, patients and carers spoke of difficulties in being "heard".

It appears that in many cases staff are uncertain of how to make use of specialist knowledge of carers (paid) in gaining information about how to recognise the meaning of non-verbal communication or how to best explain treatment/medication.

Nursing staff said that they would welcome the opportunity to gain further knowledge of this area.

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#### ➤ *Inadequate information relating to discharge*

People with learning disabilities and their carers felt that there had been inadequate information about what would happen on discharge. In particular they felt that they would like more information about recognising complications or problems and who to turn should problems arise. Carers told PALS that they were informed of discharge at the last minute making it impossible to put care arrangements in place in time.

#### ➤ *Lack of accessible information*

##### i.) Insufficient information prior to elective admission

Many patients with learning disabilities and their carers stated that they would have liked more information prior to elective admission about hospital procedure, diagnosis and treatment. They told PALS that they would like this information in the form of video or booklets with photographs. The PALS service has produced guides in this format for A & E and theatre, identified as two of the areas which caused the greatest concern but there have been problems relating to funding in getting these published.

##### ii) Inaccessible information relating to appointments and admission

Appointment letters and letters relating to admission were not found to be in an accessible format and information was not shared with carers which resulted in some admissions being missed entirely. For example, one man suffers from learning disabilities and autistic spectrum disorder. He is unable to comprehend time and asks his carers several times a day when he is going to have his surgery. The anxiety caused by not having a date for admittance manifests itself in self-harm and eating of the mail. Without the intervention of PALS on request of his carers he would not have had any way of knowing when his date for admission was to be and would have missed his surgery.

##### iii) Inadequate information relating to choices within hospital

A common experience expressed was that of being presented with a written menu for hospital meals with no other assistance in making a choice. Facilities in the hospital were not explained in a way which could be understood and patients felt too intimidated to express wishes to ward staff. For this reason, when a patient with learning disabilities is known to PALS they have been given daily visits in order to ensure that their wishes are expressed to staff.

##### iv) Inaccessible information for negotiating the hospital premises.

System of direction is very difficult for people with learning disabilities to navigate. Information about post discharge care/medication etc is inaccessible.

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- v) Communication about diagnosis and prognosis is seldom understood.
- vi) Prescription information not large enough to be read, not in an accessible format.

**"I can't understand the information on medicine bottles, it is too small, especially for people with learning disabilities. Instructions for taking tablets need to be explained otherwise I am too scared to take them!"** User Day, Manchester People First

#### **PROGRESS SO FAR**

- The PALS service currently provides some training on communication with patients with learning disabilities on the induction programme for clinical staff.
- More extensive training around communication with this client group is provided as part of the training around consent for patients with learning disabilities.
- Pictorial guides to A & E and theatre have been created but there are difficulties in producing en masse.
- PALS offers support at out-patient appointments and on the ward for all patients who feel vulnerable and this includes patients with learning disabilities. This support is provided to assist with communication and understanding of diagnosis and prognosis.
- Information needs relating to *Choose and Book* have been identified through a focus day with this patient group (cf. Appendix 1). This information has been requested by the StHA as part of their current research into ensuring accessibility of the programme and has also been forwarded to the Trust lead in this area.
- An audit of the hospital signage has been conducted by members of Manchester People First and this has been highlighted to Atkins. However, there is insufficient funding available to make significant changes.

#### **4: 1 Accident & Emergency**

- a. Problems with time spent waiting in this area. Area found to be anxiety producing for people with learning disabilities.
- b. Anxiety sometimes resulted in behaviour which was viewed as challenging. In some cases this has caused difficulties with diagnosis and treatment.
- c. Invasive medical treatment in patients with complex needs accompanied by cognitive/communication difficulties
- d. It is felt that inequitable judgments are sometimes made about quality of life issues that determine pre and post-treatment.

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**Example**

A gentleman with Learning Disabilities and severe anxiety is brought into A & E one evening (2001). He is leaning to one side and struggling to stand. There is nowhere private for him in A & E and he waits several hours to be seen. When he is seen, the Doctor says that there is nothing wrong with this patient and that he should return home. When the carer refuses, another doctor is sent for and after another couple of hours sees the patient and says that he is unable to examine the patient because he is unco-operative. This doctor suggests that the patient is either restrained or that he return home until he becomes so poorly he will no longer resist examination. The carer refuses to take the gentleman home and he waits another couple of hours until he is seen by another more senior doctor who claims that he thinks the patient has a 'brain, heart or bladder infection' and that he needs to be transferred to Withington for tests. The patient waits another two hours to be transferred to Withington, by which time he has been waiting in A & E for 12 hours!

**PROGRESS SO FAR**

- Alerts have been placed on A & E computer system relating to care needs for patients known to the learning disability partnership. The PALS system has received many enquiries from learning disability practitioners across the country about this system.
- Pictorial guide to A & E produced, cf above.
- A multi-disciplinary meeting was held in March 05 to look at the issue of invasive medical treatment and action plans have been drawn up as a result.

**4:2 Admission**

Admission for an individual with learning disabilities often requires support from the learning disability partnership and a network of carers. This often means that lengthy arrangements need to take place prior to admission and cancellation of elective surgery causes above average problems.

**PROGRESS SO FAR**

- A category of protected admission has been created for patients with complex needs and a meeting is planned between directorate manager for surgery, bed manager, learning disability partnership and PALS for June to evaluate this provision.
- PALS frequently assists with admission arrangements and communication in this area for patients with learning disabilities.

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#### **4:3 Diagnosis**

There have many concerns expressed to PALS re: lack of diagnosis of medical problems which initiated admission. It is felt that there is sometimes a diagnostic overshadowing whereby underlying problems are obscured by the learning disability.

#### **PROGRESS SO FAR**

None to date.

#### **4:4 Discharge**

There have been many concerns expressed re: discharge. Discharge often lacks sufficient planning, resulting in insufficient support being available. In some instances it has been suggested that people with learning disabilities have been discharged because their behaviour has proved difficult for ward staff to manage. It is felt by carers that patients are often discharged before clear diagnosis or understanding of medical problem/treatment has been obtained.

#### **PROGRESS SO FAR**

Revised guidelines for admission and discharge produced by learning disability partnership and included as appendix 2.

#### **4:5 Consent**

- Patients sometimes given treatment without consent being obtained.
- Confusion over capacity to consent to treatment.
- Surgery sometimes cancelled because consent has not been obtained.

#### **PROGRESS SO FAR**

- HIRS used to identify ongoing difficulties in this area
- Training provided by PALS for all staff on induction and separate study day
- Clinical guidelines created by PALS/Martin Vernon and MLDP for staff – need to be revised in light of Mental Capacity Act.

#### **4.6 In-patient care**

- Nutrition – difficulties sometimes around nutrition, especially where cognitive impairments make it difficult for patient to describe what food they will eat and what assistance they require in eating it.

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- Patients supported by learning disability partnership will usually have personal care plan with them. However, this is not being read by ward staff.
- Difficulties with pain management due to communication problems.
- Great anxiety as result of in-patient experience
- Particular problems around dysphagia – swallowing difficulties are more common in people with learning disabilities and if not managed safely, may lead to respiratory tract infections, a leading cause of early death in this client group.

Specific guidelines around dysphagia prepared for individuals with learning disabilities by experts in learning disability partnership not always utilised by staff, increasing the safety risk. for this patient group.

- Over reliance on carers – one ward told carers from the care home that they had to stay on the ward over night because of the patients challenging behaviour (this particular gentleman had never displayed challenging behaviour).
- There are some notable areas of good practice, in particular wards A5 and F3 and radiology. These areas have shown great flexibility in providing patient centred care, excellent communication skills and good liaison with community care team. Ward F3 has frequent contact with patients with learning disabilities and subsequently appears to have greater confidence amongst staff.

#### PROGRESS SO FAR

- Trust wide training currently being negotiated via modern matrons.

## **5. Recommendations**

There is a consensus of opinion on the part of people with learning disability, carers (formal and informal) and staff working in both the acute hospital and community learning disability teams that service provision has to improve. All the major reports and papers that have been written about this subject area cover the same issues.

The greatest challenge remains to embed this work across the Trust rather than in the isolated work of a few champions.

The recommendations to emerge from this evidence are summarised in the table below.

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<b>Objective</b>	<b>Action</b>	<b>Benefit</b>	<b>Rationale/ evidence base</b>	<b>performance indicators</b>	<b>Timescale</b>	<b>person responsible</b>
<p><b>1. Strategy</b></p> <p>1.1 A senior manager and Trust board member to have lead responsibility for overseeing implementation of policies and protocols relating to care of patients with a learning disability within the Trust</p>	<p>Trust board member to lead on overseeing of progress on Valuing People, Better Metrics, etc</p> <p>Clinical governance agenda to continue to monitor issues regarding admission of people with a learning disability</p>	<p>Comprehensive and Trust wide approach to this patient group will improve care for all patients in the hospital. Complaints, HIRS and PALS will be minimised.</p>	<p>.</p>	<p>Person identified</p>	<p>September 05</p>	
<p>1.2 Obtain figures for number of people with a learning disability who access Trust.</p>	<p>Draw up actions for optimum way of gathering information with audit, user groups and learning disability partnership.</p>	<p>Trust will be able to evidence base action taken. Issue of learning disabilities will be included on Trust agenda in recognition of number of patients accessing hospital</p>	<p>Identification of people with a learning disability is a target of the White Paper Valuing People DOH 2004</p>	<p>Quantitative evidence of number of patients with learning disabilities using Trust services obtained.</p>	<p>June 06</p>	<p>EC/MLDP</p>

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<u>Objective</u>	<u>Action</u>	<u>Benefit</u>	<u>Rationale/ evidence base</u>	<u>Performance indicators</u>	<u>Timescale</u>	<u>Responsibility</u>
<p><b>.2.0 Communication</b></p> <p>2.1 Accessible, clear, up-to-date information using a variety of methods is available at an appropriate time to support access.</p>	<p>All new Trust produced information to include symbols. User friendly information sheets available. “No words booklets” to have identified funding to enable roll out across the Trust.</p>	<p>Improved practice around informed consent.</p> <p>Benefits also for patients with English as a second language and those unable to read.</p> <p>Greater clinical effectiveness</p> <p>All new information is accessible.</p>	<p><b><u>Health care standards</u></b> Domain 1 : Safety Domain 2: Clinical and cost effectiveness Domain 3: Governance Domain 4: Patient focus</p> <p><b><u>NPSA report 2004</u></b> identified risks created by inaccessible information</p>	<p>Greater wealth of information in variety of formats.</p>	<p>June 06</p>	<p>Elaine Clark</p>
<p>2.2 Training around communication to be compiled and produced in partnership with patients and carers.</p>	<p>Training programme to be agreed and methods for access to training.</p>				<p>October 05</p>	<p>Elaine Clark/ Cheryl Brook</p>
<p>2.3 Support to be provided to ensure person with learning disabilities remains an active and valued member of the Trust editorial board.</p>	<p>Communication with Manchester People First to determine support needs.</p>					<p>Elaine Clark/Des Chow</p>

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<u>Recommendation</u>	<u>Action</u>	<u>Benefit</u>	<u>Rationale/Evidence Base</u>	<u>Performance indicators</u>	<u>Timescale</u>	<u>Person responsible</u>
2.4 Menu sheets to be made user friendly with pictures or explanations	Discussion with Sodexo re: best way forward.	All patients will benefit, especially those who cannot read. Reduces stress and anxiety.  Nutritional needs of wider range of patients met.	Essence of care – nutrition  Health care standards: Domain 4 – patient focus	Menu sheets with symbols/pictures	October 05	Elaine Clark
<b>3.0 Training</b> 3.1 Awareness training to be delivered to all staff	All staff to be delivered training on learning disability, disability and equality on a regular basis. A commitment at a senior level to ensure that staff are released for training  Explore best way to deliver – CLDT? MLDP	Greater understanding of issues facing people with a learning disability when they are admitted to hospital.	Health Care Stds: Domain 1: Safety Domain 4: Patient Focus  Valuing People	Number of staff who have received this training.	July 06	Elaine clark/ Cheryl brook/Des Chow/ MLDP

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Objective	Action	Benefit	Rationale/Evidence base	Performance indicators	Timescale	Responsible person
<p><b>4.0 Clinical management</b> 4.1 Clinical staff to be familiar with issues around consent and capacity <a href="http://www.doh.gov/consent">www.doh.gov/consent</a></p>	<p>Clinical staff to attend training on consent and capacity. Audio cassette recordings of patient interview with Consultant, therapist, nurse when required</p>		<p>NPSA : identified safety issues of physical restraint and vulnerability of patients with learning disabilities</p> <p>Health Care Stds: Domain 1: Safety</p>	<p>Number of staff who have received training on consent.</p>	<p>Achieved and ongoing</p>	<p>Elaine Clark</p>
<p>4.3 Once the specialist/consultant nurse has been informed of their appointment date, patient and where appropriate carers, professionals or services involved in that person will be contacted discuss any specific problems that may be caused by their attendance at hospital. Any such problems can then be addressed prior to their appointment.</p>	<p>Discuss with managers of surgery and out-patient services.</p>	<p>Reduction in DNAs</p>		<p>Reduction in DNAs</p>	<p>January 06</p>	<p>Elaine Clark</p>
<p>4.4 Appropriate support is available to assist the patient with personal care, feeding, drinking and communication.</p>	<p>Essence of care issues. Full assessment of nursing required with all assistance delivered as and when required.</p>	<p>The patient's stay is facilitated and supported making it more enjoyable and reducing stress in the process.</p>	<p>Essence of care nutrition Health care stds: Domain 4 – Patient focus</p>	<p>Reduction in issues relating to nutrition highlighted through PALS</p>	<p>Achieved and ongoing</p>	<p>Elaine Clark/ Christine Miles</p>

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RECOMMENDATION	ACTION	BENEFIT	RATIONALE EVIDENCE BASE	PERFORMANCE INDICATORS	TIMESCALE	PERSON RESPONSIBLE
<p>Minimal waiting times in Out Patients.</p> <p>In Accident and Emergency patients to be triaged urgently</p> <p>5. <b><u>LIAISON</u></b> 5.1 PALS to promote improved hospital services for people with a learning disability.</p>	<p>Alert system in A &amp; E to continue to be developed for this patient group.</p> <p>"Valuing People" states that PALS will work with CLDTs. PALS to maintain relationship with CLDTs. PALS leaflet to be accessible to people with learning disabilities.</p>	<p>Greater accessibility of acute services for patients with learning disabilities. Some people are not able to comprehend the concept of time. A minimal waiting time will facilitate any necessary investigations as stress may be reduced.</p> <p>Improved partnership working with community learning disability team/advocacy groups/patients and carers</p>	<p>Valuing People</p> <p>Health Care Stds: Domain 1 – safety Domain 4 – patient focus</p>	<p>Evidence highlighted through patient stories suggests improved access and experience.</p>	<p>Achieved and ongoing.</p>	<p>EC</p> <p>MLDP</p>
<p>5.2 Trust to have representative on local Learning Disability Partnership Board</p>	<p>Achieved</p>	<p>Greater co-operative working across boundaries</p>	<p>Health Care Stds: Domain 4 – Patient focus</p>	<p>Trust member on board</p>	<p>Achieved and ongoing</p>	<p>EC</p>

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## Bibliography

Atkinson and Scarloff (1984) *Acute Hospital Wards and the disabled patient*

Barr, O. (1997) Care of people with learning disabilities in hospitals. *Nursing Standard*, 12(8): 49-56.

Cumella, S. & Martin, D. (2000) *Secondary Healthcare for People with a Learning Disability. A report completed for the Department of Health.* (available at [www.fons.org/networks/nnlndn/a2a](http://www.fons.org/networks/nnlndn/a2a))

Department of Health (2004) *Better Metrics*, London: Department of Health

Department of Health (1999) *Signposts to success*, London: Department of Health

Department of Health (2001) *Valuing People. A new strategy for learning disability for 21<sup>st</sup> century*, London: Department of Health.

Department of Health (2005) *National Standards, Local Action: Health and Social Care Standards and Planning Framework 2005/6 – 2007/8* London: Department of Health

National Patient Safety Agency: (2004) *Understanding the Patient Safety Issues for patients with learning disabilities.*

**Appendix 1 -  
Consultations on Consent and  
Choose and Book**

**“Fair for all and personal to you”.  
Consultation with patients with  
Learning Disabilities and their carers -  
June 2004**

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**“Fair for all and personal to you”.**

**Consultation with patients with Learning Disabilities and their carers - June 2004**

**Background**

The Department of Health White Paper Valuing People (2001) stressed the need for greater choice in the lives of people with Learning Disabilities and their carers, people with learning disabilities should be able to “..access a health service designed around individual needs with fast and convenient care delivered to consistently high standard” (objective for health) whilst the recent Mencap report “Treat me right” (2004) highlighted the inequities which exist within a health care setting for patients with learning disabilities as a result of lack of inclusion and lack of choice.

In 2001 the Government made the pledge in its manifesto to “..give patients more choice” and in 2003 the government extended this pledge (Building on the Best: choice, responsiveness and equity in the NHS) by stating that “we want choice, information and the power of personal preference extended to the many”. It is important that patient choice and services extend to everyone, including those most at risk of exclusion such as patients with learning disabilities. For this to happen it is vital that we listen to what the patients and the public are telling us.

In June 2004, as part of an ongoing process of consultation with people with learning disabilities South Manchester University Hospitals Trust PALS service and Manchester People First held a day working with people with Learning Disabilities to discover what they would need in terms of support and resources to be enabled to make choices around health care.

**Methodology**

1. Anonymised case histories brought to SMUHT PALS and highlighting difficulties experienced by patients with learning disabilities in exercising choice.
2. A day was held at Manchester People First inviting people with learning disabilities and their carers to discuss how they could access “Choice” . Fifty people attended and the day was divided into:
  - a) Group work - patients with learning disabilities, their carers and South Manchester University Hospitals Trust discussed the difficulties in exercising choice and the factors which would help.
  - b) Use of drama (patients with learning disabilities and staff from South Manchester University Hospitals Trust) to stimulate discussion and provoke answers to the following four main questions:
    - I) How does it feel to be a patient with a learning disability?
    - II) What information is necessary in order for somebody with a learning disability to be able to exercise choice?
    - III) How should this information be presented?
    - IV) What else could help?

**Findings**

**1. How do you feel as a patient with a learning disability seeking treatment from an Acute Trust?**

Uncomfortable  
Nervous  
Scared  
Unhappy  
Confused  
Ignored  
Not confident  
Insulted  
Lonely  
Uncared for  
Without choice  
Without understanding

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**2. What information would enable somebody with a learning disability to exercise choice?**

Information about the hospital - location  
Facilities - phones, tv, books, volunteers?  
Availability of specialised equipment  
Areas of special expertise  
Food/special diets - availability of  
Cleanliness  
Waiting times for treatment

What are the staff like - pictures and names on the wall would be useful

Will staff make extra time for me?

Do staff have understanding of learning disabilities?

How good is disabled access?

What is the parking like?

What are the visiting hours/access for visitors?

What is the star rating?

Are the nurses pretty?

Is there a learning disability nurse in place?

Can pre-hospital visits be arranged?

Is there a PALS service?

What are the good points and the bad points?

**3. How should this information be presented?**

Video

Audio

Webpage

Leaflets with words and pictures

There should be someone who will talk to you and help you think through any concerns

Roadshow

Drop-in centre that you can go to for advice

Helpline (telephone information line)

Information library - with information on all the various hospitals

It would be useful to ask a user group of people with learning disabilities to review hospitals and write a "users guide".

**4. What other factors could help?**

Health promotion events at which people from various hospitals could come and talk

PALS - more of them

Counselling services

Advice centres with people who are trained to work with people with learning disabilities

Information packs about various hospitals which could be taken home and discussed with family and friends.

For health authorities to meet with user groups and listen to people with learning disabilities

Support from the moment choice is offered and at every stage of the patient journey.

It would be useful if there was a FREEFONE number which could be utilised in order to gain additional information/support.

**Recommendations**

Although this was only a very small scale consultation some key themes emerged which have been echoed on the wider stage. All of the patients and carers questioned felt concern over the implications of Choice and fear that this would heighten their exclusion from health services. In particular concerns were expressed re: availability of sufficient information and in a suitable format, availability of support from suitably trained individuals and provision of time to make choices.

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The following recommendations are ways in which the process of choice can be facilitated for patients with learning disabilities:

1. Awareness raising opportunities for staff working in Acute care and employed by the Choice programme in relation to communication and people with a learning disability would help to ensure people could make the right choices about health care.
2. Patient Advice and Liaison Service officers need to have chances to develop skills and knowledge to assist them in their work to increase choice with individuals with a learning disability in NHS services.
3. If PALS officers are to be one of the sources of information and support for individuals seeking to exercise choice it is vital that they have sufficient resources.
4. It is important that information about hospital services are available in a variety of formats and languages and in large print.
5. It is important that sufficient time is built into the Choice process to allow for discussion and support from family members, members of community learning disability teams and friends.
6. The provision of pre-admission/pre-choice visits to acute trusts would be welcomed by people with learning disabilities and is something which has been successfully offered by South Manchester University Hospitals Trust.
7. The involvement of people with learning disabilities in the preparation of information about the acute trust to involve a users perspective is an important factor which should be incorporated.

#### **Suggestions for future research**

1. This was research on a very small scale and is purely qualitative. It would be useful to conduct further research with a larger number of participants to provide quantitative data.
2. It will be important to conduct research in the early stages of the Choice programme to determine the extent to which patients with learning disabilities are being supported to make Choices and to determine what action is required to make choice a real possibility for all.

#### **Bibliography**

Fair for all, personal to you	Department of Health	2003
Building on the best, Choice, responsiveness and equity in the NHS	Department of Health	2003
Treat me right	Mencap	2004