Royal Surrey County Hospital NHS Foundation Trust

Learning Disabilities Policy

Policy to Support People with Learning Disabilities to Access

Mirroring Acute Hospital Services Across Surrey

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Name of Review/ Development Body:	Learning Disability Steering Group
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Reviewing Officer:	Lauren Bowller/Jenny Watkins

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Version Control Sheet

Date	Review Type (please tick)		Version No.	Author of Review	Title of Author	Date Ratified	Ratification Body	Page Numbers (where amended)	Line Numbers (where amended)	Details of change	
	Minor amendment	[1]Full Review								Inserted	Deleted
June 2011	N/A	New Policy	3.2	Kathryn Fisher	Acute Learning Disability Liaison Nurse	June 2011	Trust Board			N/A	N/A
September 2017		√	3.3	Lauren Bowller/Jenny Watkins	Acute Learning Disability Liaison Nurse	September 2017	Safeguarding Adult Steering Group			Amended to new Policy format and guidance & references up-dated	

1. Introduction

This policy was initially developed and ratified by the Surrey Learning Disability Steering Group which represents the five acute trusts including Royal Surrey County Hospital NHS Foundation Trust.

The policy addresses a number of important issues for people with learning disabilities (LD) when using Royal Surrey County Hospital. This includes equality of access, easy to understand information, best interest decision making and the role of the Acute and Community Learning Disability Liaison Nurses, and support staff. It has been adopted for use at the RSCH in the interests of sharing good practice.

People with learning disabilities have a right to the same level of health care as that provided to the general population. This care should be flexible and responsive and any diagnosis or treatment must take account of specific needs associated with the person's learning disability. (Reference Health Care for All 2008 pg. 14 and CQC Fundamental Standards 2015)

For people with learning disabilities who use the services provided by Royal Surrey County Hospital NHS Foundation Trust (RSCH) responsibility for the delivery of that care will remain with the hospital for the duration of the individual's treatment.

Background:

The White Paper Valuing People: a new strategy for learning disability for the 21st Century was published in 2001. Valuing People focuses on the importance of improving the health of people with learning disabilities. The Department of Health's objective is "to enable people with learning disabilities to have access to a health services designed around their individual needs with fast and convenient care delivered to a consistently high standard and with additional support where necessary".

In 2003 the Valuing People Support Team issued All Means All, reinforcing the entitlement of people with learning disabilities to access high quality mainstream health services. Also in 2003, the action guide Valuing Health for All (Primary Care Trusts and the Health of People with Learning Disabilities) was published. Valuing Health for All focuses on the action that Primary Care Trusts (PCTs) should take with their partners to reduce health inequalities for people with learning disabilities. Since the restructuring of health in 2013 this responsibility has been taken over by Clinical Commissioning Groups (CCG)

The National Patient Safety Agency (NPSA) published Understanding the Patient Safety Issues for People with Learning Disabilities in 2004. The NPSA identifies five patient safety priorities including:

- The vulnerability of people with learning disabilities in general hospital
- The lack of accessible information
- Illness or disease being miss or un-diagnosed
- Dysphagia
- The use of physical interventions

All priorities have potential relevance for people with learning disabilities attending hospital.

The "Death by Indifference" report (2007) by Mencap highlighted the deaths of 6 people with learning disability following their care in acute hospitals in the NHS,

exposing institutional discrimination. Following this Sir Jonathan Michael's Healthcare for All report (July 2008) made a number of recommendations including:

- raising awareness of the barriers people with learning disability face when accessing healthcare,
- making reasonable adjustments to the care pathway,
- provide training on the Mental Capacity Act,
- make information accessible to enable patients with learning disability to maximize their opportunity to participate in the care and decision making process

Valuing people now was published in 2009

The Confidential enquiry into the premature deaths of people with learning disabilities (2014) reviewed the deaths of 247 people with Learning Disabilities in a 2 year period. 43% of these deaths were unexpected and many were related to delays or problems with diagnosis or treatment; and problems identifying needs and providing appropriate care in response to changing needs. The CIPOLD study has shown the continuing need to identify people with learning disabilities in healthcare settings, and to record, implement and audit provision of 'reasonable adjustments' to avoid serious disadvantage. Adherence to the Mental Capacity Act (2005) was poor and assumptions of quality of life led to inappropriate use of DNACPR. This policy helps to address these issues within The Royal Surrey County Hospital and in turn enhance the delivery of care to patients with Learning Disabilities.

2. Purpose and Objectives

The main purpose of this policy is to ensure that people with learning disabilities are able to access high quality health care when attending RSCH for diagnostic investigations or treatment.

Further aims are:

To enable staff at the acute Trust to develop a better understanding of people with learning disabilities and to equip them to deal more effectively with the particular needs of each individual

To clarify for paid and un-paid staff attending hospital with a person with learning disabilities their supporting/caring role and the boundaries between their caring role and the nursing role of the professional hospital staff.

To support LD staff in their roles

To further embed the use of the Hospital Passport for people with learning disabilities using hospital services

Support the implementation of the LD identification flagging alert.

To provide an opportunity for hospital and learning disability staff to work together to develop

- Effective communication
- Training
- Awareness raising of the particular needs of a person with learning disability
- Easy to understand information for service users.
- Identify and implement reasonable adjustments

3. Scope

Definitions:
The term “Learning Disability (LD)” is used to describe a person who has developmental delay or intellectual disabilities which are usually evident from birth or early childhood.

There are three core criteria, which must be met for the term learning disability to apply:

- Significant impairment of intellectual function
- Significant impairment of adaptive and or social function (ability to cope on a day to day basis with the demands of his/her environment and the expectations of age and culture)
- Age of onset before adulthood.

Learning disabilities does not include:

- The development of intellectual, social or adaptive impairments after the age of 18.
- Brain injury acquired after the age of 18
- Complex medical conditions that affect intellectual and social/ adaptive functioning: e.g. dementias, Huntington’s chorea
- Specific learning difficulties: e.g. dyslexia, literacy or dyscalculia, or delayed speech and language development.

The term “Learning Difficulties” which is often used in educational services to describe people with specific learning problems does not indicate that a person has a learning disability as defined above.
Community Learning Disability Teams provide specialist support for adults with an assessed learning disability as described above who are eligible to receive services

People with learning disabilities may present as having:

- Difficulties communicating and expressing needs and choices
- Difficulty understanding their diagnosis, treatment options or services available to them
- Difficulty understanding the consequences their decisions can have on their health status
- Difficulties in adapting to a hospital environment and the expectations of hospital staff

4. Duties and Responsibilities

4.1 Chief Executive

Has a responsibility for ensuring that all reasonable measures are taken to ensure that people with learning disability receive care appropriate to their needs.

4.2 Director of Nursing and Patient Experience

Has Board level responsibility for the patients experience and is responsible for ensuring that systems and processes are in place to ensure this policy is adhered to.

4.3 Medical Director

Has the responsibility to ensure that all medical teams are aware of and adhere to this policy, and is available to give senior clinical opinion in complex cases.

4.4 Deputy Directors of Operations/ Heads of Nursing/ Matrons/Ward Managers/ Heads of Departments/ Clinical Site Managers

Are responsible for circulation of this policy and ensuring there is local compliance with this policy in their portfolio, wards and departments to safeguard the patient and to ensure their needs are met.

4.5 Trust Employees

Have the responsibility to comply with this policy; ensuring patients are referred to the Learning Disability Liaison Nurse.

4.6 Acute Liaison Learning Disability Nurse.

To work collaboratively with health care and multi-agency colleagues to facilitate open and easy access for People with Learning disabilities to acute services. Providing specialist nursing advice and training as appropriate to enable the development of services sensitive to and appropriate for the needs of individuals with learning disabilities. To promote awareness and implementation of reasonable adjustments and to work in collaboration with the CCG to identify patients with a Learning Disability through the e-referrals system. To work in partnership with the Community Learning Disability Team (CTPLD) to support patients with LD accessing the hospital and to make appropriate referrals on discharge.

5. Subject matter of the policy

5.1 Care pathways

The protocol suggests two pathways for patients with learning disabilities using hospital services. These are one for planned admissions to hospital and the second for emergency admissions via the Accident and Emergency Department or Emergency Assessment Unit. These care pathways are included at Appendix 1

The key priorities identified for either pathway:

- Early referral to the Learning Disability Liaison Team
- Providing support and guidance to hospital staff in order to meet the needs of people with learning disabilities.
- Providing easy to understand information for service users with learning disabilities about their treatment and their hospital stay
- Support for people with learning disabilities at any point of their

hospital journey
- Encouraging staff to make reasonable adjustments to care where required
- Understanding Mental Capacity Act and the application of Capacity assessments and Best Interest decision making regarding treatment options
- Involvement and engagement with families and other carers in assessment of need and planning care and interventions

This work will be discussed and progressed at the Trust Learning Disability Steering Group which is a multidisciplinary group both internally and externally represented. This group in turn reports into the Trust's Adult Safeguarding Committee.

5.2 Communication

Many barriers to healthcare can be overcome by effective communication. Health staff will need to communicate effectively not only with the person with a learning disability but with support staff, family
members, advocates, care managers, learning disability team staff and other professionals.
Many people with learning disabilities have difficulties with communication. This may include problems with expression, articulation, comprehension, and coping with social situations. People with learning disabilities have difficulties understanding complex sentences and abstract concepts with time being a particularly difficult concept to comprehend. This should be considered when discussing appointments or future treatments. It can be helpful to relate appointments to concrete events in the person's life. They may also have difficulty understanding written communication and this should be taken into consideration when arranging appointments, particularly if pre-appointment instructions are included.

Many are unable to communicate verbally and rely on other methods such as gesture, pointing or facial expression to communicate their needs. Problems with communication are often linked to behavior which can be challenging can then present a barrier to accessing appropriate health care.

An individual's capacity to understand and communicate can be affected by a number of factors, including anxiety, pain and distress, unfamiliar people and environments. People with learning disabilities may also be unable to adequately describe their symptoms, degree and site of discomfort and may inform staff that they feel fine even when clearly unwell.

There are a number of strategies which can assist in ensuring more effective communication when meeting a person with learning disabilities for the first time. These are detailed in the hospital communication book, a copy of which is in every ward Learning Disability resource folder. Additional information can also be found on the Safeguarding Icon on the desktop in the LD folder. Easy read information can be accessed via the desktop as well as generic

communication tools. In addition easy read information can be developed for individual.

"This is me, My care passport" provides clear and concise information in an easy to understand format regarding the person's support needs. Patients bring this document with them into hospital. If a patient does not have a completed passport these are available in LD folder within the Safeguarding folder on the desktop and also in the LD resource folders in the wards and departments.

5.3 Consent and best interest decision making

5.3.1 Capacity to consent to medical treatment

People with learning disabilities may have particular difficulties in relation to decision making for some of the following reasons:

- Difficulty understanding relevant information, which is linked to the person's verbal and general cognitive skills (e.g. difficulties with attention, distractibility) and the methods used to convey information
- Difficulty retaining relevant information
- Difficulty appreciating the personal significance of information
- Difficulty with reasoning and use of information to arrive at a decision (e.g. concreteness, difficulties with abstracting and generalising)
- Lack of experience of decision making
- Tendency to acquiescence and suggestibility, and difficulties being assertive
- Emotional factors such as fear and anxiety
- Difficulties in expressing choices.

Some of these difficulties relate to the person's learning disability in that their cognitive function is limited in some areas. Others reflect the person's social and psychological experience (e.g. relative powerlessness) and represent "secondary handicaps". Staff also need to ensure that they present the information in a way that is appropriate for each individual patient.

Please refer to the trusts mental capacity and best interest folder on the trust desktop for further information.

5.3.2 Consent to treatment and determining best interest

Please refer to the Trust Mental Capacity and Consent Policy available via the trusts intranet.

5.3.3 Resolution of disputes (Escalation Process)

If there is significant disagreement regarding the treatment of a patient who may lack capacity, the courts have identified certain circumstances when healthcare professionals or others must make an application to the Court of Protection.

These are:

- Where there is serious uncertainty about the patient's capacity to consent, or their best interests; or
- Where there is serious unresolved disagreement between a patient's family and health professionals.

If consensus cannot be reached, or if someone wishes to challenge a

determination about best interests made by a decision–maker, there are a number of options that could be explored, including:

- Involving an advocate who is independent of all the parties involved in the decision to act on behalf of the person lacking capacity (Independent Mental Capacity Advocate)
- Getting a second opinion (for medical treatment)
- Holding a formal or informal case conference
- Attempting mediation – though reaching consensus will not necessarily determine best interests of the person lacking capacity.

If there is disagreement between learning disability staff, and the hospital team about the proposed treatment or non–treatment of a person with a learning disability, the concerns should be raised initially with the ward manager and the Consultant responsible for the patient. Learning disability service staff should also raise their concerns with their line manager and the Consultant responsible for the care and the Acute Liaison Nurse who can support with best interest discussions and the IMCA. Hospital staff should escalate their concerns through the relevant Matron, the Acute Liaison Nurse and the safeguarding team.

Further information regarding this can be found in the safeguarding folder on RSCH desktop. Best interest paperwork on shared drive

5.4 Do Not Resuscitate

A decision to complete a DNACPR for patients with a learning disability should be treated in the same manner as for any other patient, i.e. there should be discussion with the patient themselves if appropriate and families and other carers to gain a wider view of quality of life and previously expressed wishes, values & beliefs.

Please refer to ‘Cardiopulmonary Resuscitation Policy and decisions relating to this – January 2016’.

5.5 Complaints

Service users and/or carers should be supported to use the hospital’s complaints procedure if there are concerns that cannot be addressed by ward or clinic staff. The procedures and communication should be in a format that the person with learning disabilities can understand. The Patient Advice and Liaison Service (PALS) can assist with addressing concerns and issues on behalf of service users and carers. Their service provides a central point of contact where patients, relatives and carers can obtain a wide range of information about the hospital services as well as guidance on accessing other health information. Patients, relatives and carers are also able to involve this service if there should be any issues or concerns that arise that can be resolved informally by discussion with hospital staff. PALS will support service users and carers to access and use the hospital complaints procedure if required or provide information on independent advocacy services if needed. PALS can also support with access to interpreters or adapted information to support people with additional needs.

Contact details: See appendix 3

5.6 Preparation for hospital visits, admissions and discharge

The Equality Act 2010 states that reasonable adjustments must be made for people with learning disabilities when accessing hospital services. This may include longer appointments, booking first appointment of the day, quiet places to wait for appointments, carers staying with patients overnight, use of appropriate written information. This information should be available on Oasis on the flagging system (Red Diamond)

Many people with learning disabilities are very anxious about medical treatment and hospital environments and this anxiety can sometimes be expressed in behavior which can be challenging for staff to manage. Please remember any form of behavior is a form of communication and is often the only expression of anxiety available to an individual.

Prior to any planned hospital appointment or admission, the individual's families and/or carers can contact the Acute LD Liaison Nurse for support. Admission meetings can be arranged and visits to the relevant departments.

As highlighted in the 'Working Together 2' guidelines (2015) an admission planning maybe required to ensure all reasonable adjustments and pathways to admission can be discussed prior to the person coming into hospital. This should include significant others in the persons care. Additional needs for planned admission should be highlighted by the pre-assessment team and referral made to the Learning Disability Liaison Nurse. For inpatients, discharge meetings should be offered to include all relevant others in the persons care in addition to representation from the medical team, nursing staff and therapists. This will enable a safe discharge home and ensure the patients' needs are communicated appropriately on discharge. This meeting should be arranged be by staff on the ward.

Patients/carers and/or the person with learning disabilities are expected to ensure that all relevant information, including the patients 'This is Me' passport, details of medication or any specialist advice or guidelines are made available to hospital staff on or before admission. If the patient does not have this information, staff can contact the residential /nursing home and the patients' family/carer directly to request this information. If they are still having difficulty obtaining this information, they can contact the Acute Liaison Nurse for support.

Not everyone with a learning disability will be known to community LD teams but staff can contact the teams to check if people are known and to make referrals if there is a need.

Contact details: - see Appendix 3

5.6.1 Out-patient Appointments

The Out Patient Department can be contacted prior to appointment if specialist equipment and/or services are required. The service user and/or their carer can give the Care Passport to their named/clinic nurse on arrival and prior to consultation.

The named/ clinic nurse will assist during the consultation and will be available post consultation to provide extra information and direct the service user and their carer to other hospital departments as required.

In cases where the service user presents with distress, extreme anxiety or challenging behavior in hospital settings follow up appointments should be avoided unless clinically essential. If a follow up appointment is not offered, care arrangements should be discussed and negotiated with the Acute Liaison Nurse (if involved) who can liaise as necessary with the GP. Acute Liaison Nurses can provide support for follow up appointments if needed.

If there is no involvement from the CTPLD then discussion should take place directly with individual's' GP

The Acute Liaison Nurse will ensure that they liaise with the relevant named/clinic nurse or consultant and/or identified contact, as appropriate, in order to plan how the appointment will proceed. Where service users present with phobias/extreme anxieties or challenging behavior, consideration to the following areas are a necessity in order to meet their health needs:

Avoid waiting around as this may exacerbate anxiety levels/ challenging behavior. First appointments should be offered when the clinic usually quieter. Consider using the bleep system for the service user and carer which allows them to leave the department and to return nearer to the time of being seen.

- Where available, single rooms/or suitably quiet waiting area should be offered to minimise anxiety levels and avoid risks to other patients' safety.
- Sedation should be planned in advance as needed.
- Where the client is likely to exhibit challenging behaviour, the learning disability staff will liaise with the relevant nursing/medical staff to fully risk assess and plan how they can jointly manage these risky situations. It should not be assumed that the learning disability staff will manage all situations independently.
- Reasonable adjustments to meet the patients need should be undertaken.

This information may best be obtained during an admission planning meeting.

5.6.2 Routine Planned Admissions (including day surgery)

On receipt of the referral card, the hospital will contact the patient with learning disabilities/carer to negotiate a date for a pre-operative assessment and ask them to bring the My Care Passport to the clinic appointment. If translation services are required this will be arranged by the carers and the unit, and if any specialist equipment is needed the unit will provide this for the

clinic. Any special requirements for the patient will be identified at the pre-assessment clinic in addition to the LD flag on Oasis.

If it is established that the person has a learning disability, consent should be sought verbally or by using the "flagging paperwork" and a flag should be put onto the OASIS system indicating the reasonable adjustments needed (Red Diamond).
The scheduling team will negotiate a date for surgery with the patient/carer that is mutually convenient. Transport requirements can be arranged at this point if there is a clinical need. The acute liaison nurse should be made aware of the planned admission date.

On the day of surgery the service user/carer should bring the My Care Passport and hand to the named nurse who will be looking after the patient.

Consideration should be given to combine procedures, wherever possible. During anaesthesia there could be opportunities to undertake blood tests or other procedures to avoid any further distress to the patient. These should be discussed fully before surgery and may require a best interest decision being made

Pre-assessment appointments should be planned with as much time before admission as possible to ascertain information on patient and required care levels to disseminate to the admitting ward.

A side room should be considered if the patient requires a quiet environment or may struggle in the ward environment. Please also consider additional equipment that may be necessary i.e. a reclining chair if a carer is staying overnight. The learning disability staff will negotiate between relevant carers and hospital staff to review all aspects of support needed within the hospital environment.

Liaison between relevant disciplines, e.g. Occupational Therapy (OT), Speech and Language Therapy (SLT) and Physiotherapy (PT) will be established as needed and, if further support required, this will be agreed, e.g. joint working between community and hospital therapy staff. If joint working is agreed, clinical responsibility rests with hospital staff who will determine the appropriate treatment for the person with a learning disability, with LD clinicians providing a support role.

5.6.3 Urgent or Emergency Admissions

Emergency admissions will usually be admitted via an out-patient clinic, Accident and Emergency (A&E) Department or through the Emergency Assessment Unit (EAU)

If possible when admitted carers should provide the This is Me, My Care Passport to the clinic nurse or the nurse in charge in A&E or EAU who will be able to assist the individual with their needs.

A&E and EAU admissions - if the LD Liaison Nurse is aware that a service user may need to access A&E or EAU, then they will contact the nurse in charge/consultant and/or identified contact within these departments if it is anticipated that the service user may have some significant problems.

For service users with phobias and or challenging behaviors, support will need to be negotiated on a one to one basis.

There will be emergency admissions of service users with learning disabilities that the Acute LD Liaison Nurse will not be aware of. The departments should make the Acute Liaison Nurse aware that the person is in the department. Out of hours, the departments should contact the on call duty Social Worker who can identify the client and their care requirements and discuss how any apparent support needs can best be met.

Contact Details: - see appendix 2

5.6.4 Discharge Planning

On admission a service user and/or their carer will be advised of a provisional date for their discharge. This date will be reviewed on a daily basis and may involve a number of the hospital team. The nurse in charge will liaise with the individual and/or their carer about safe discharge to home from hospital.
The relevant case manager should be informed of any admission of a person with a learning disability and dialogue established with the carers, Acute Liaison Nurse and Care Manager. Any factors which may prevent discharge back to the person's home should be flagged to the Ward Sister/Matron as soon as possible.

Discharge planning meetings should be offered to all patients with a learning disability accessing the hospital as outlined in 'Working together 2' (2015)

This may be due to a significant change in the patient's health needs or when there are many other professionals and carers involved in the persons care. The care providers involved may have to co-ordinate training for carers to manage the changing health need. A review of the social care package may be necessary and consideration given to the need for temporary respite care or a permanent alternative placement.

5.7 Sharing information

All patients have a right to privacy and to control information about themselves. Where the person lacks capacity, this right must be balanced with protection of their interests. Although carer's will be involved in best interest decisions, there should not be widespread disclosure of personal health information without the person's valid consent and information should be shared on a need to know basis.

Information pertinent to any change in the person's support needs should be

shared with the care provider, but detailed clinical information should be treated sensitively and disclosed only when necessary and to those who need to know it.

It must not be assumed that the person's next of kin is the primary carer. Many people with learning disabilities live in registered care homes or supported environments and the care provider is responsible for the health and wellbeing of the service user. Care staff would expect to be involved in best interest discussions where the person with a learning disability lacks capacity. Many people with learning disabilities have limited or intermittent contact with family members therefore care should be taken to ensure that information is disclosed appropriately and with the relevant people.

Service users should be consulted about who they wish to be included in discussions about clinical matters. Clinical information will be shared as appropriate by professional colleagues, i.e. therapist to therapist, etc. to ensure continuity of care. Key professionals involved in the person's care are highlighted in the Care Passport.

Patients with learning disability should be offered the opportunity to have a flag placed on the hospital electronic system (OASIS) to alert staff to the fact that the person has a learning disability. This will allow hospital staff to ensure they have made reasonable adjustments to the care provided. If the patient lacks capacity to make this decision, a best interest decision can be made.

5.8 The role of Community Paid Care Staff

The role of paid/unpaid carers, family members and acute staff is highlighted in the 'Working Together 2' (2015) document. People with learning disabilities have the right to the same level of medical and nursing care as that provided to the general population. However, due to their complex care needs, they may require additional staffing support to meet their particular needs. The responsibility for providing medical and nursing care remains with the hospital. When the person with a learning disability is in residential care, an agreement with the learning disability service that routinely provide care for the individual should be approached regarding support required. They may offer to support service users as appropriate with issues related to their learning disability and can be consulted for advice regarding this. Learning disability paid staff can work alongside hospital staff, in agreement with the home manager and the Ward Matron, to ensure the service user's support needs are met. This support would include any personal tasks with which a support worker would normally be involved while caring for a person at home. This would not include any nursing procedures. The learning disability staff should also ensure that any specialist equipment that the service user needs is transferred to the hospital e.g. seating systems, wheelchairs, eating and drinking equipment, communication aids, etc. Learning disability paid care staff should not be expected to agree to clinical procedures on behalf of the service user, however, they can be consulted. Staff should consider offering the 'Carer Passport' as appropriate

5.8.1 Funding for Additional Support

The purpose of this protocol is to identify how people with learning disabilities can best be supported to use the services provided by RSCH. The protocol includes advice about the type of support that might be needed by some people but it does not describe in detail the procedure that should be followed in order to acquire any additional funding. This should be discussed on a case by case basis with the relevant organizations.

5.9 Autism

Autism is a spectrum condition and affects approximately 700,000 people in the UK. There is a high prevalence of Autism in the Learning Disability population therefore it should be considered within this policy. The main 3 areas of difficulties experienced by people with Autism are: Social Communication, Social Interaction and Social imagination. People with Autism require reasonable adjustments to be made to their care when accessing the hospital. Autism training is delivered within the Learning Disability Training sessions on Trust Induction. Further information on Autism can be found in the Learning Disability Shared Folder located in the Safeguarding Folder. (Think Autism: 2014)

5.10 Challenging behavior

Approximately 7 – 15% of people with a LD display challenging behavior. It is more likely to occur in those with communication difficulties. Challenging behavior occurs for a reason. It often occurs to get the individuals needs met. Challenging behavior is more likely to occur in hospitals as it is an unfamiliar environment and can cause the person anxieties. Reasons for such behavior include: pain, avoiding situations/people, accessing preferred objects, frustration, lack of understanding and communication difficulties. The behavior displayed may be self-injury, destructiveness, non-compliance, verbal/physical aggression and stereotyped behaviors. It may be displayed as this is the only way the patient can communicate their needs and wishes. This presentation can lead to diagnostic overshadowing where once a behavioral diagnosis is made there is a tendency to attribute all other problems to that diagnosis, thereby leaving other co-existing conditions undiagnosed.

Further information on challenging behavior can be found in the Learning Disability Shared Folder located in the Safeguarding Folder.

5.11 Risk Assessment

The learning disability risk assessment tool offers a framework to assist in deciding if an additional support is needed to reduce risk during a hospital stay. It aims to identify risk with a person centered approach and ensure measures are in place to reduce likelihood of such risk. It is recommended that the Risk Assessment is used by the nursing staff on the ward and the Learning Disability Liaison Nurse alongside the patient and their families, carers and advocates. A surrey wide risk assessment has been developed in partnership with Surrey and Borders Partnership NHS Foundation Trust. Staff are encouraged to use this on the wards alongside The Royal Surrey patient risk assessment booklet.

The risk assessment is available in the learning disability resource files, the

LD shared folder on the desk top or requested from the Acute Liaison Disabilities Nurse.

6. Training

Awareness of learning disability training is provided on the Trust Clinical Induction program, Health Care Assistant induction, medical team and individual training to specific hospital departments. In addition the trust provides ad hoc LD study days.

7. Implementation

The policy has already been implemented and this is a review. There will be a notification through e-round up to inform staff that it has been reviewed. The Acute LD Liaison Nurse will raise awareness of the policy in her contact with clinical staff and during induction for new staff.

8. Monitoring of compliance with and effectiveness of the policy

All issues relating to care of patients with learning disability will be discussed at the Learning Disability Steering Group. All relevant issues will also be discussed within the Safeguarding Adults committee.

The Acute Liaison Nurse will discuss specific cases, issues and or concerns with the Safeguarding Adults Lead and/ or the Deputy Director of Nursing for Quality and Patient Experience.

The Acute Liaison Nurse will meet regularly with the Deputy Director of Nursing to review the action plan and add any issues arising.

9. Review, Approval, Ratification and Archiving

The policy will be reviewed every three years or earlier if national guidance changes.

The Local Policy Officer is responsible for ensuring that archive copies of superseded working documents are retained in accordance with the Records Management: NHS Code of Practice, 2015 refer to Policy Development and Management: including policies, procedures, protocols, guidelines, pathways and other procedural documents.

10. Dissemination and publication

Dissemination of the final Policy is the responsibility of the author. They must ensure the Policy is uploaded to the Trust's Central Library (intranet) via their Local Policy Officer.

The Head of Marketing and Communication is responsible for the Trust-wide notification of existence of the Policy.

11. Equality Impact Analysis

The author of this policy has undertaken an equality and diversity impact assessment

and has concluded there is no impact identified (Appendix 6). This policy applies to all patients irrespective of age, ethnicity, and gender, social, cultural, psychological and physical needs.

12. Associated Documents

This policy should be read in conjunction with the following RSCH Trust policies:

- Mental Capacity Act
- Privacy and Dignity Policy
- Consent Policy
- Adult Safeguarding Policy
- Cardiopulmonary Resuscitation Policy and decisions relating to this.

13. References

Nursing and Midwifery (NMC) Code of Conduct - 2015

Department of Health, (2008) Healthcare for All. Sir Johnathan Michaels report - http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_106126.pdf

Department of Health, (2003) All Means All – Valuing People Support Team

Department of Health, (2003) Valuing Health for All (PCTs and Health of People with learning Disabilities)

Department of Health, (2001) Valuing People: a new strategy for Learning Disability for the 21st Century – Department of Health

Understanding the Patient Safety Issues for People with Learning Disabilities – National

Patient Safety Agency (NPSA), 2004

Equal Treatment: Closing the Gap – Disability Rights Commission, September 2006

Promoting Access to Healthcare for people with a learning disability – a guide for frontline NHS staff. Best Practice Statement. NHS Quality Improvement Scotland 2006

Making Decisions: Helping People who have difficulty deciding for themselves _ A Guide for Healthcare Professionals - Lord Chancellors Department May 2003

Mental Capacity Act 2005 Guidance – Booklets are currently available from the Department for Constitutional Affairs and will be revised in 2007.

Closing the Gap: 2006 DRC

Death by Indifference – Mencap 2006

Valuing People Now – DoH 2007
Six lives: the provision of public services to people with learning disabilities Ann Abraham

Parliamentary and Health Service Ombudsman March 2009

74 deaths and counting – Mencap (2012)

Working together 2: Easy steps to improve support for people with learning disabilities in hospital (2015)
https://www.improvinghealthandlives.org.uk/publications/1247/Working_together_2:_Easy_steps_to_improve_support_for_people_with_learning_disabilities_in_hospital

Confidential Enquiry into premature deaths of people with Learning Disabilities (CIPOLD) – 2013 – www.bristol.ac.uk/cipold

Equality Act (2010)

Surrey Health Action: Easy Read Health information and leaflets:
http://www.surreyhealthaction.org/

Easy Read Health Information: www.easyhealth.org.uk

Think Autism: fulfilling and rewarding lives, the strategy for adults with autism in England: April 2014

Appendix 1

Admission Pathway

Emergency Admission

Family/Support Staff - contact with A&E

- If carers are present ask them for the person's hospital passport to be brought to A&E
- If coming by ambulance check for the massage in a bottle information
- Ask cares to provide an up to date list of medication chart

Further Information

- Check for a flag on the system and any additional care requirements or reasonable adjustment identified
- Contact liason Nurse Ext 2524

Triage

- Contact Liaison Nurse
- Consult with support staff/family and the hospital passport regarding the person's usual persentation and their means communication. In particular relating to pain on acute trauma.
- Some people with a learning disability will become more withdrawn when injured and others may become more vocal and physical when expressing pain.

Waiting Time/Locaton

- Consider if access to a quier area may be if benefit to the person to minimize distress
- Be mindful that you do not isolate the person and that they can summon assistance if needed
- Can they and will they use the buzzer to get help, if not and there is no care consider a 1-a or a more visible location.

Fast Tracking

- A person can be fast tracked if deemed appropriate by the admitting doctor/triage nurse

Admission to the ward

- Shere the Hospital Passport with the ward to make them aware of the persons additional needs revert to planned admission pathway

Discharge

- When discharging from A&E ensure that the person has support at home not everyone with a learning disability lives in a staffed enviroment, some may only have care for 2-3 hours per week and may share a house with other with a learning disability
- Family carers may not be able to cope with increased care requirement as they may not have any social care ath home

Planned Admission & Discharge

Preparing for Admission

- Is the person flagged as having a learning disability
- Hospital Ward to make contact with the person as far in advance as possible so that arrangement can be made
- Person assessed at Pre admission
- Discuss issues of Consent, does the person have capscity to consent to the treatment/ does a best interest meeting need to ake place
- Does the person have hospital passport, if not complete with the person and or their carer or request passport to be completed and broought on admission
- Discuss any accessible informtion needed to support the client. Discuss with LD Liaison nurse on site
- Think what additional care will be required to facilitate discharge home. Conatct Care managemnet to start funding process for additional social care hours.

Reasonable adjustments

- Visit the ward / department as this may reduce anxiety for the person coming to the ward and their family/ support staff and enable questions to be asked prior to admission
- Contact Liaison Nurse for support
- Discuss level and type of support needed for the person's stay
- Does the person need 1-1. Think who is most appropriate to provide support.
- Discuss carer's role on the ward during the stay
- Identify reasonable adjustments to facilitate stay i.e. Bed for carer if staying overnight, meals etc.
- Patient priority

Admission to Ward

- Shere completed Patient passport with ward staff
- Ensure there is an up to date medication list

Complete Care Plan

- The patient passport will assist with the person's care plan; this will ensure that the person's everyday needs are adressed and met
- Consider area of risk pain identification and managemnt. This will help to reduce diagnostic overshadowing.

Discharge Planning Meeting

Discharge planning will begin at the point of admission with an estimated discharge date. As soon as discharge is being considered contact the family/support staff/care manager involved with the person and the discharge planning team. Ensure that all aspects of the person's care are discussed and an action plan agreed to meed the needs of the person at discharge. Ensure an Immediate discharge letter is completed and faxed to the GP given to support staff and Liaison Nurse prior to discharge. Ensure family /support staff are aware of any medication changes or that any new medication regime is fully understood and checked at point of discharge (this will contain 14 or 28 days to last until their next prescription. Agree for a dosette box to be provided as necessary.

Royal Surrey County Hospital NHS Foundation Trust

Appendix 2

Acute Liaison Nursing Service for People with Learning Disabilities

ROYAL SURREY COUNTY HOSPITAL

Contact Number: 07717850308

Or Via the main switchboard on Ext: 2545 **Bleep:** 71-2545

What do Acute Liaison Nurses do?

As Acute Learning Disability Liaison Nurses we can provide advice and support for people with learning Disability who are in contact with acute hospital services in Surrey as well as to their family carers, paid staff and acute staff.

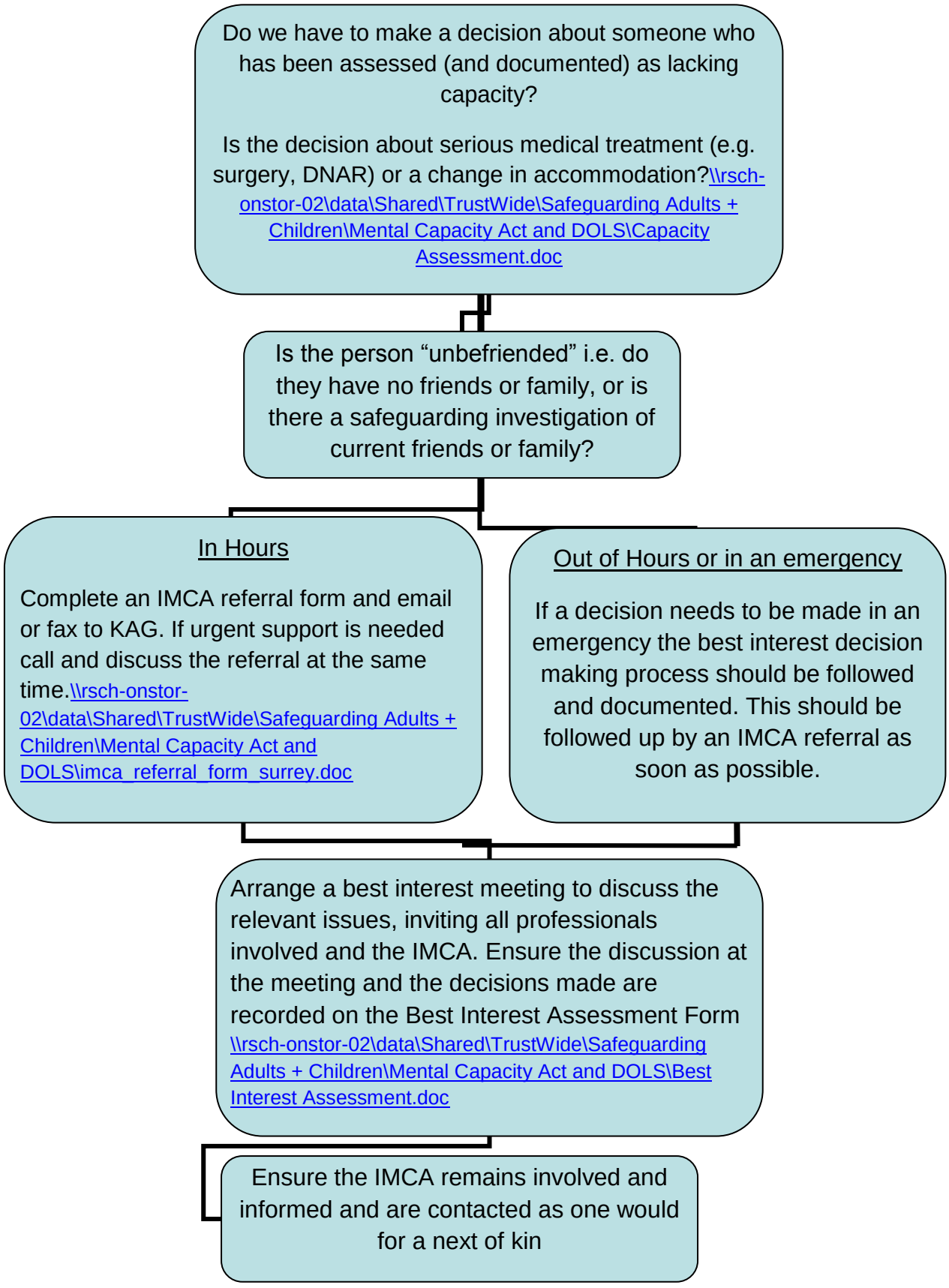
This may include:

- Helping people with learning disabilities have access to information in an easy read format.
- Providing support and guidance to hospital staff in to meet the needs of people with learning disabilities.
- Co-coordinating the care of someone with a learning disability at any point of their hospital journey.
- Helping someone with learning disabilities prepare for their hospital visit and/ or stay.
- Providing training opportunities to acute staff regarding the needs of people with learning disabilities.
- Encouraging acute staff to make reasonable adjustments to care where required.
- Providing advice around Mental Capacity Act including capacity assessments, best interest decisions, and referring to Independent Mental Capacity Advocates (IMCA)
- Support the discharge process.
- Sign post to other services as required.

Appendix 3
Other Contact Details

Service	Details
Community Learning Disability Team West :	01252 335555
Kingston Advocacy Group :	0208 5491028
Learning Disability Nurse	07717 850308 X2545
Surrey County Council Learning Disability Care Management Team SW :	01483 5174626
PALS:	ext. 2059 or direct line 01483 402757 or email: rsc-tr.pals@nhs.net

Appendix 4
IMCA Flowchart


Do we have to make a decision about someone who has been assessed (and documented) as lacking capacity?
Is the decision about serious medical treatment (e.g. surgery, DNAR) or a change in accommodation?\\rsch-onstor-02\data\Shared\TrustWide\Safeguarding Adults + Children\Mental Capacity Act and DOLS\Capacity Assessment.doc
Is the person "unbefriended" i.e. do they have no friends or family, or is there a safeguarding investigation of current friends or family?
In Hours
Complete an IMCA referral form and email or fax to KAG. If urgent support is needed call and discuss the referral at the same time.\\rsch-onstor-02\data\Shared\TrustWide\Safeguarding Adults + Children\Mental Capacity Act and DOLS\imca_referral_form_surrey.doc
Out of Hours or in an emergency
If a decision needs to be made in an emergency the best interest decision making process should be followed and documented. This should be followed up by an IMCA referral as soon as possible.
Arrange a best interest meeting to discuss the relevant issues, inviting all professionals involved and the IMCA. Ensure the discussion at the meeting and the decisions made are recorded on the Best Interest Assessment Form \\rsch-onstor-02\data\Shared\TrustWide\Safeguarding Adults + Children\Mental Capacity Act and DOLS\Best Interest Assessment.doc
Ensure the IMCA remains involved and informed and are contacted as one would for a next of kin

Risk Assessment for Patient's With Learning Disabilities

Please complete this form for all patients admitted with a Learning Disability. Please complete with the person or their family/carer. For further support on completing this assessment please contact Lauren Bowller – Learning Disability Liaison Nurse – 07717 85308

Topic	Likelihood (Please tick)		
Communication	Unlikely	Likely	Almost certainly
Level of Learning disability	Please tick (If Known)		
	Mild	Moderate	Severe	Profound
Does this person have a Lasting Power of Attorney, Enduring Power of Attorney, Court Appointed Deputy, IMCA or Advocate? If yes please specify.			
Unable to understand instruction			
Unable to communicate needs			
Unable to communicate pain			
Requires communication aids, including sign support, easy read pictorial information, longer time spent with me.	Please specify:		
Requires communication support (from Hospital staff, carer, someone who knows me well)	Parent / Carer	Hospital staff	Someone who knows me well
Additional sensory issue i.e. blind or deaf	Please specify:		
Environmental	Unlikely	Likely	Almost certainly
At Risk of altering equipment i.e. machinery on ward, suction , Oxygen etc.			
Busy / Crowded areas			

Topic	Likelihood (Please tick)		
Nutrition / Hydration	Unlikely	Likely	Almost certainly
Unable to eat or drink without full assistance			
Unable to eat or drink safely without direct supervision.			
Unable to eat or drink independently without prompting and or assistance with lids etc.			
At risk of choking			
Has current feeding guideline	Yes		No	
Requires review by Speech and Language Therapy	Yes		No	
Problems coping with nil by mouth and fasting i.e. unable to follow guidance, at risk of consuming other people's food / fluids			
Has PEG and is at risk of aspiration due to positioning.			
At risk of consumption of harmful substances			

Risk Assessment for Patient's With Learning Disabilities

Topic	Likelihood (Please Tick)		
Personal safety	Unlikely	Likely	Almost certainly
At risk of getting lost			
Risk of falling			
Risk of getting out of bed			
Medications / Treatments	Unlikely	Likely	Almost certainly
Unable to comply with medication / treatment / interventions administration			
At risk of removal of drips/ tubing			
At risk of removal of dressings / casts etc.			
Agitation and Aggression	Unlikely	Likely	Almost certainly
Physical Aggression			
Verbal Aggression			
Self-injurious behaviour			
Destructive behaviour			

Mental Health- Memory, depression, anxiety, fear	Unlikely	Likely	Almost certainly
Experiences Anxiety, Isolation, Fear			
Experiences Memory difficulties			
Experiences Mental Illness	Diagnosis (if known)		

Epilepsy	Please Tick			
Known to have Epilepsy	Yes		No	
Has Epilepsy Protocol	Yes		No	
Seizure monitoring chart put in place	Signed:		Date:	

Reasonable adjustments made as a result of this assessment (Please tick)

Communication support	**Communication Book**		**Hospital passport**	
	Easy read Information		**Carer support**	
Environment	Alternative environment i.e. bay / side room		Alternative waiting area	
	Additional 1:1 Support		Desensitisation Visits	
General Adjustments	Admission protocols		Prioritising (Expedite) through system	
	Flag / Alert on IT system		Other (Please specify)	

Please consider the risks identified above for this individual and then consider the level of support this person may require to minimise these risks. This may include, additional support (1:1), higher level of supervision within the bay, risks at specific times i.e. night time, familiar care staff, higher level of nursing care i.e. continence, nutritional and pressure care. Please discuss this further with the nurse in charge or Matron as appropriate.

Risk Assessment for Patient's With Learning Disabilities

Additional comments – measures put in place to manage / reduce identified risk :

Completed By:_____ Designation: _____ Date:_____

Appendix 6

Equality Impact Assessment

Care Group/ Department	**Nursing and Patient Experience**
Title of Person Auditing Policy/Service	**Deputy Director of Nursing**
Policy Title/Service	**Learning Difficulties Policy**
Policy/Service Purpose	

The checklist below will help you to see any strength and /or highlight improvements required to ensure that the policy/service is compliant.

Check for discrimination	**DIRECT discrimination against any minority group of SERVICE USERS or EMPLOYEES**			**INDIRECT discrimination against any minority groups of SERVICE USERS or EMPLOYEES**		
	Response (Yes/No)	**Action Required ? (Yes/No)**	**Resource implications?**	**Response (Yes/No)**	**Action Required? (Yes/No)**	**Resource implications?**
Age?	**No**	**No**	**No**	**No**	**No**	**No**
Gender? (Female, Male, Transsexual)	**No**	**No**	**No**	**No**	**No**	**No**
Disability?	**Yes**	**Yes**	**Yes**	**No**	**No**	**No**
Race or ethnicity?	**No**	**No**	**No**	**No**	**No**	**No**
Religion/Faith/Spiritual belief?	**No**	**No**	**No**	**No**	**No**	**No**
Sexual Orientation?	**No**	**No**	**No**	**No**	**No**	**No**

All policies will be placed on the intranet/internet to ensure flexibility of access under the Freedom of Information Act 2000. Efforts will be made to make policies and information available in alternative mediums or by alternative means to meet individual needs on request to departments or via the PALs Department (Ext 2059).

Level of Impact: Total number of items answered 'yes' indicating discrimination
Score: High/Medium/Low

High	**Medium**	**Low**
0	**0**	**0**

The following supplementary questions are to be answered for an impact assessment of employee policies/ patient services – if there is a negative response to any of the questions a full impact assessment should be completed.

Questions	Yes/No	Comments
Are there any access issues for disabled people e.g. physically, entry criteria, complexity of access	**no**	
Are there any recorded complaints relating to equality issues in the last three months?	**no**	
Has a patient/staff survey highlighted any issues?	**no**	
Does analysis of the take up of services raise any issues when studied against local statistics? / **Does analysis of the application of policies raise any**	**no**	

issues when studied against the employee statistics for the whole Trust?		
Do outcome statistics compromise any group?	**no**	
Is there a non-attendance issue in any particular group?	**no**	
Is the service/policy focused on any particular group and is that 'justified'?	**yes**	**To improve the care of people with disabilities**
Are any special services/policy available or in place to accommodate specific groups? Is there a need for them?	**yes**	
Is privacy available if requested? (services only)	**yes**	

Name of author/auditors: