UNIVERSITY HOSPITALS COVENTRY AND WARWICKSHIRE NHS TRUST

REPORT TO COVENTRY CITY COUNCIL ADULT SOCIAL CARE AND HEALTH OVERVIEW AND SCRUTINY COMMITTEE

5th March 2014

Subject: Care of Patient with Learning Disabilities	
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Accountable Executive Director:	Professor Mark Radford, Chief Nursing Officer

GLOSSARY

Abbreviation	In Full
MENCAP	The voice of learning disability
DOH	Department of Health
CIPOLD	Confidential Inquiring into Pre-mature Death of People with a Learning Disability
GP	General Practitioner
IMCA	Independent Mental Capacity Advocates
DNACPR	Do Not Attempt Cardiac Pulmonary Resuscitation
CRRS	Clinical Results Recording System
DOLS	Deprivation of Liberty Safeguarding
MCA	Mental Capacity Act
BIM	Best Interest Meeting
ASD	Autistic Spectrum Disorder
OPA	Outpatient Appointment
AL	Acute Liasion
BI	Best Interest
PRE-MED	Pre medication
GA	General Anaesthetic
LD	Learning Disability
OLM	Oracle Learning Management
AHP	Allied Healthcare Professional
CSB	Clinical Sciences Building
SALT	Speech and Language Therapy
EPR	Electronic Patient Record

WRITTEN REPORT (provided in addition to cover sheet)?

🗌 No

🖂 No

X Yes

Yes

POWERPOINT PRESENTATION?

NB Presentations need to be submitted for inclusion in papers

Title Approx. Length

PURPOSE OF THE REPORT / PRESENTATION:

To provide an overview of the work being undertaken at UHCW in relation to the development of pathways of care and enhancing the experiences of patients with a learning disability who access services and receive care at UHCW.

SUMMARY OF KEY ISSUES:

There have been a number of reports and inquires published since 2001 relating to the care received by people with learning disabilities.

The key findings are that the quality and effectiveness of health and social care afforded to people with learning disabilities has been shown to be deficient in a number of ways according to numerous investigations and reports. All of which had implications for providers of care.

In 2013, the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD 2013) has been published, and has suggested that the care of people with a learning disability in the period leading up to their death could be considered sub optimal when compared with that of the general population.

All of the reports and inquires have made similar recommendations; this reports outlines these and then provides an overview of work undertaken or in progress relating to the care and experience of adult people with learning disabilities accessing services at UHCW and recommendations for further review and action.

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The report identifies areas of good practice in particular partnership working with Acute Liaison Team, Education and Training and reasonable adjustments and areas for improvement key being

- o Enhanced identification of patients with a learning disability
- o Process for trigger serious incident or mortality review for people with learning disabilities
- User involvement

SUMMARY OF KEY RISKS:

None compliance with recommendations Poor experience and outcomes healthcare

1. Purpose of the Report

To provide an overview of the work being undertaken at UHCW in relation to the development of pathways of care and enhancing the experiences of patients with a learning disability who access services and receive care at UHCW.

2. Introduction

Valuing People (2001) and Valuing People Now (2009), when detailing the government's strategy for learning disability services, has maintained as one of its central themes that people with learning disability have the same human rights as everyone else and have the right to equal access to healthcare and also to improving health outcomes.

The quality and effectiveness of health and social care afforded to people with learning disabilities has been shown to be deficient in a number of ways according to numerous investigations and reports. All of which had implications for providers of care.

In 2007, *Death by Indifference* (MENCAP 2007) reported on deaths of six people with a learning disability that were connected to failings in the NHS Care, this triggered an independent inquiry and investigation of the six deaths by the Parliamentary and Health Services Ombudsman. The recommendations from this were reported in Six Lives: the provision of public services to people with learning disabilities in 2009. (DOH 2009).

In 2010, Six Lives Progress report was published (DOH 2010).

In 2012, MENCAP produced a report *Death by Indifference: 74 death and counting* (MENCAP 2012) which identifies steps that have been taken as a result and what still remains to be done. The key findings were:

- Setting up of Confidential Inquiry into Premature Death of People with Learning Disabilities
- Creation of the Public Observatory Improving Health and Lives: Learning Disability Observatory
- Introduction of annual health checks via the Directed Enhanced Services
- Creation of a self assessment framework
- No consistency in flagging system across country
- Lack of understanding reasonable adjustments
- Lack of basic care
- Poor communication
- Delays in diagnosis and treatment
- Failure to recognise pain
- Do not resuscitate orders and Mental Capacity

In 2013, the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD 2013) has been published, and has suggested that the care of people with a learning disability in the period leading up to their death could be considered sub optimal when compared with that of the general population. The report investigated the sequence of events leading to all known death of people with learning disabilities (aged 4 years and older) in 5 Primary Care Trust areas of South West England that occurred over a 2 year period 2010-2012. It also reviewed the deaths of people without learning disabilities who died at similar ages to place the findings in context.

The median age of death for people with learning disabilities (65 years for men and 63 years for women) was significantly less than the UK population (78 years for men and 83 years for women). Overall 22% were under the age of 50 when they died.

A number of factors were identified that contributed to vulnerability and premature death of people with learning disabilities:

- Significant difficulty or delay in diagnosis, further investigation or specialist referral
- Problems with treatment
- Lack of reasonable adjustments to facilitate healthcare particularly attendance clinic appointments and investigations
- GP referrals not identifying learning disability
- Hospital 'flagging' systems to identify people with learning disabilities who needed reasonable adjustments
- Lack of coordinated care across and between different disease pathways and service providers.
- Lack of adherence and understanding of the Mental Capacity Act 2005 by both health and social care providers in particular assessment of capacity, the process of making 'best interest' decisions and when an Independent Mental Capacity Advocate (IMCA) should be appointed.
- Record keeping was commonly deficient particularly in relation to fluid intake, nutrition, weight, seizures and little attention given to predicting problems e.g. when a person fearful of contact with medical professionals
- Lack of recognition of approaching end of life led to problems in coordinating care and providing support to the person and family.
- Difficulties in providing Continuing Healthcare (CHC) funding.

The study showed that despite previous reports many professionals are unaware or do not include in their usual practice approaches that adapt services to meet the needs of people with learning disabilities. That there is a continuing need to identify people with learning disabilities in healthcare settings, and to record, implement and audit the provision of 'reasonable' adjustments.

The key recommendations from the review were:

- 1. clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems
- 2. reasonable adjustments required by and provided to individuals to be audited annually and examples of best practice shared across agencies and organisations
- 3. NICE Guidelines to take into account multi-morbidity
- 4. a named healthcare professional to be allocated to people with complex or multiple health needs or two more long term conditions
- 5. patient held records to be introduced and given to all patients with learning disabilities who have multiple healthcare conditions
- 6. standardise Annual Health Checks and a clear pathway between Health Action Plans
- 7. people with learning disabilities to have access to the same investigations and treatments as anyone else but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome
- 8. barrier in individuals' access to healthcare to be addressed by proactive referral to specialist learning disability services
- 9. adults with learning disabilities to be considered a high risk group for death from respiratory problems
- 10. mental Capacity advice to be available 24 hours a day

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- 11. Mental Capacity training and regular updates to be mandatory for staff involved in the delivery of health and social care
- 12. DNACPR guidelines to be more clearly defined and standardised across England
- 13. Advanced health and care planning to be prioritised. Commissioning processes to take this into account and to be flexible and responsive to change.
- 14. all decisions that a person with learning disabilities is to receive palliative care only to be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team
- 15. improved systems to be put into place nationally for the collection of standardised mortality data about people with a learning disability.
- 16. systems to be put into place to ensure that local learning disability mortality data is analysed and published on population profiles and joint Strategic Needs Assessments
- 17. A National Learning Disability Review body to be established.

The findings from this confidential inquiry and some of the recommendations were consistent with those identified in previous reports.

In 2011 a group of experienced Quality of Life Auditors with disabilities from Changing Our Lives, a charity based in Sandwell supports people with learning disabilities to speak up for their rights and take control of their lives developed Quality of Health Principles, related to:

- 1. Accessible communication
- 2. Information
- 3. Choice
- 4. Admission
- 5. Staying in hospital
- 6. Discharge
- 7. Appointments
- 8. Treatments
- 9. The way healthcare professionals work with me
- 10. Accessible environment
- 11. Privacy and dignity
- 12. Respect
- 13. Medication
- 14. Complaints

These principles should underpin the care delivered to all people accessing healthcare and the recommendations from the inquires implemented into practice to improve the access to healthcare and the outcomes of people with learning disabilities

At UHCW there has been a significant amount of work undertaken aimed at improving the pathways and experience of patients with a learning disability who access our services in line with recommendations outlined. The next section will provide and overview of some of this work areas of good practice and areas for further improvement utilising the recommendations from the confidential inquiry as a framework.

3. Progress at University Hospitals Coventry and Warwickshire NHS Trust

University Hospitals Coventry and Warwickshire NHS Trust has developed strong partnership working with the Acute Liaison Team - Coventry and Warwickshire Partnership Trust, Grapevine and IMCA to support people who have a learning disability who receive care at UHCW.

The partnership working has raised awareness with clinical staff at UHCW of the specific needs of people receiving care who have a learning disability and their carers and provides a support mechanism to patients, carers and staff.

3.1 Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems

Alerts - A requirement of the Care Quality Commission is that trusts have in place a system to alert patients with learning disabilities. In partnership with the Partnership Trust a system was implemented that identifies named individuals when patients access or are admitted from the Emergency Department, have outpatient's appointments or are scheduled to be admitted. This systems as worked well but access is restricted to named individuals and is dependent upon data sharing with the partnership trust – with changes in community services the databases have not been merged between organisations so the information is no longer up to date. This means that UHCW is no longer compliant with this requirement. Plans were in place to introduce ALERTS onto CRRS but these have been shelved. Further meetings are being held to resolve.

3.2 reasonable adjustments required by and provided to individuals to be audited annually and examples of best practice shared across agencies and organisations

It is a requirement that services should make 'reasonable adjustments' to ensure people with a disability can get equal outcomes. They are usually very easily made. At last years Commissioning for Quality Learning Disability Health Assessment Peer review UHCW was praised for the range of reasonable adjustments that were made – these ranged from extra clinic time, accommodating and involvement of carers in care delivery to allowing specialised equipment to be brought into hospital for use by patient, involvement of IMCA services and best interest meetings.

Specialist support – if a patient admitted with a learning disability requires additional or specialist support/supervision whilst an in-patient a Dependency Rating Scale is conducted to assist nurses to identify the special care needs and that maybe present. If it is identified that specialist external support is needed UHCW funds this support.

Care Pathways - Development and implementation of specialist pathways for patients with a learning disability accessing specific services e.g. dental surgery, ophthalmic surgery, Audiology, day surgery

3.3 A named healthcare coordinator to be allocated to people with complex or multiple needs

There are not designated learning disabilities named nurse. One of the Associate Directors of Nursing leads on learning disability issues with the support of a Practice Facilitator and in collaboration with the Acute Liaison Team.

Acute Liaison Team – consists of registered learning disability nurses and Assistant Practitioner who are provided and funded by Coventry and Warwickshire Partnership Trust. They provide an in reach service, hold honorary contracts with UHCW and have a base here. They work as part of the wider community learning disability team which has proved to be valuable in terms of improving awareness, communication and quality

of services. It has enabled improved access to wider services and as facilitated discharge planning. The role of the team includes:

- Receiving referrals and providing advice to staff
- Working alongside staff to recommend and implement any reasonable adjustments
- Supporting the implementation of the mental capacity act including IMCA
- Enhanced communication between the patient, carers and healthcare professionals
- Working alongside carers and family during the hospital stay
- Facilitate development of services
- Raise awareness of learning disabilities and the acute liaison role through training etc

Between April 2012 and March 2013 the Acute Liaison Team has received approximately 95 referrals for advice or to review people admitted to hospital with a Learning Disability. Appendix 1 provides a case study example of the work they are involved.

Learning Disabilities Awareness Steering Group – this has been in place for several years. Membership consists of representatives from Modern Matrons at UHCW, IMCA, Grapevine, Learning Disabilities Acute Liaison Team, Carers Forum, Practice Facilitators, Safeguarding and Patient Experience chaired by Associate Director of Nursing Education and Research. The group meet bimonthly unfortunately UHCW representation from practice as diminished significantly and requires reenergising

Learning Disability Link workers/champions - have been identified from ward and departments to work with the Acute Liaison team to raise awareness of learning disabilities care. The plan is to hold annual updates and to have representation on the Learning Disabilities Steering Group.

3.4 patient held records to be introduced and given to all patients with learning disabilities who have multiple healthcare conditions

Communication - A Hospital Passport was developed by the Acute Liaison Team adapted from a number of other documents utilised by other organisations. It is a communication tools which provides basic but fundamental information about the person, and their health and support needs. It is intended that it is completed at the time of their health check in the community and would then bring it with them to hospital. The aim being to ensure that the person with a learning disability gets appropriate care whilst in hospital. If person admitted to hospital and does not have one then this can be completed at that time and passports are available.

3.5 people with learning disabilities to have access to the same investigations and treatments as anyone else but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome

It has been identified that a lack of reasonable adjustments to facilitate healthcare for people with a learning disability especially attendance at outpatient appointments and investigations was a contributory factor in a number of deaths.

Some of the practices in place relating to reasonable adjustments that have been taken within the Trust have been identified. Ways that reasonable adjustments are promoted are:

- Availability of easy read leaflets on the learning disability intranet page.
- Clinical guidelines
- Longer appointment times if required
- Support of Acute Liaison Team, IMCA
- Learning Disability Link Staff
- A DVD has been developed as an information resource for patients accessing services at UHCW this is being developed in partnership with Grapevine. George Elliott Hospital Warwickshire NHS Trust and Coventry and Warwickshire Partnership Trust.
- Involvement of people with a learning disability in the education and training of staff
- Carers and patients visiting clinical area prior to hospital attendance to reduce anxiety.
- Education and training

Education and Training – This is a key element to ensure staff in practice understands the special needs/considerations of people accessing acute care with a learning disability, resources that are available to support them in their practice and to ensure that patients with a learning disability have a positive experience. Initiatives that have been undertaken are:

- Development and implementation of resources that is accessible via the hospital intranet.
- A number of training CD's and resource folders have been reviewed that could be utilised in practice.
- Interactive session on Effective Care Practices for Support Workers and newly Qualified Nurse Preceptorship Programme.
- Mental Capacity Training
- Raising awareness sessions have been undertaken utilising "the roving board concept" which has enabled the Acute Liaison Team to visit clinical areas to introduce themselves and raise awareness caring for patients with learning disability.
- Learning Disabilities Awareness work involved series of workshops and interactive sessions supported by Grapevine.
- Power training as recently been commenced which involved 5 minute delivery on key points. These being:
 - 1. values and misconceptions
 - 2. Carers
 - 3. Capacity and consent
 - 4. Communication
 - 5. Reasonable adjustments (being flexible)

(see appendix 2)

3.5 mental Capacity advice to be available 24 hours a day

There are Senior Nurse are duty 24 hrs a day who can provide and advice with issues relating to mental capacity. Advice is also available Monday to Friday for Safeguarding Vulnerable Adult Lead, the Dementia Nurse Specialist, the Acute Liaison Team and

IMCA. Detailed information and all relevant documentation necessary to comply with the Mental Capacity Act is available under Safeguarding Dept on the Intranet.

3.6 Mental Capacity training and regular updates to be mandatory for staff involved in the delivery of health and social care

Mental Capacity training is part of the induction for new staff. It is available as an elearning package but is not currently mandatory and is referenced within mandatory safeguarding training.

The safeguarding lead does provide 1:1 small group sessions as requested in relation to mental capacity and DOLLS.

A new consent document has been developed which included assessment of capacity and best interest decisions. This is to be rolled out across the Trust and will include staff training.

Within the Trust there are excellent examples of assessment of capacity and best interest decision by specialities e.g ophthalmology and maxillo facial.

3.7 all decisions that a person with learning disabilities is to receive palliative care only to be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team

The Pallative Care Team have been involved in informing care through the Learning Disabilities Steering Group and are involved in care of patients in hospital. A review of this aspect of care is required to identify current position and if there are any gaps.

3.8 Systems to be put into place to ensure that local learning disability mortality data is analysed and published on population profiles and joint Strategic Needs Assessments

A previous recommendation was that deaths and serious incidents involving patients with a learning disability should be considered as a potential trigger for a detailed review and this was to be part of mortality reviews. The latest inquiry identified that adults with learning disabilities should be considered a high risk group for death from respiratory problems. Further work needs to be undertaken to look at deaths that have occurred and whether any preventative measures could have been put in place i.e assessment for risk of aspiration, swallow assessment.

4. Additional Activity

4.1 Patient Experience – capturing the views of people with a learning disability who have accessed the service is a challenge.

- A patients satisfaction questionnaire How Did We Do" was initially implemented and given to patient/carers before discharge the return rate was very poor.
- The Impressions system was then being reviewed to establish if it could be adapted for access by patients with a learning disability. This has not been possible.
- The Friends and Family Test would need to be adapted.
- Further work is required to identify how the experience of people learning disability can be captured and should be a part of the wider patient experience agenda.

4.2 Complaints - The current complaints system is being reviewed and evaluated as to it user friendliness compared with other organisations. It is considered to be user friendly There as only been one complaint made this year and that was resolved locally. There was a complaint investigated by the Ombudsman and the conclusion was that there was no further action to be taken.

4.3 Monitoring

- Development and implementation of benchmarks that reflect the Care Quality Commissions Performance Indicators and the compliance monitoring framework for acute trusts. These being:
 - 1. Does the NHS trust have a mechanism in place to identify and flag patients with learning disabilities and protocols that ensure that pathways of care are reasonably adjusted to meet the health needs of these patients?
 - Does the NHS trust provide readily available and comprehensible information to patients with learning disabilities about the following criteria?:
 treatment options;
 - complaints procedures: and
 - appointments.
 - 3. Does the NHS trust have protocols in place to provide suitable support for family carers who support patients with learning disabilities?
 - 4. Does the NHS trust have protocols in place to routinely include training on providing healthcare to patients with learning disabilities for all staff?
 - 5. Does the NHS trust have protocols in place to encourage representation of people with learning disabilities and their family carers?
 - Does the NHS trust have protocols in place to regularly audit its practices for patients with learning disabilities and to demonstrate the findings in routine public reports? The benchmarking is currently being undertaken for 2013/14.

6. Recommendations

- To review the current system for identification of patients with a learning disability who access acute care in particular those who require reasonable adjustments to be made. Some organisations are now able to identify through their Patient Administration Systems.
- That each speciality undertakes a review of pathways of care to ensure that they include reasonable adjustments for people with a learning disability.
- Review of literature and patient information to ensure that it is accessible to people with a learning disability.
- All clinical staff to receive training and updates in relation to learning disability awareness, communication techniques for working for working with people with learning disability and relevant legislation; the Mental Capacity Act and what it says about decision making, consent, best interest meetings etc as part of induction and continuing professional development.

- Ensure that the reasonable adjustments necessary are in place to enable people with a learning disability to raise complaints regarding their care and treatment, that systems in place for handling and investigating complaints are robust and that they are appropriately engage the complainant, users and carers/family.
- Review of deaths and serious incidents involving patients with a learning disability,
- Continue to build on partnership working with Coventry and Warwickshire Partnership Trust's Acute Liaison Team. Grapevine and IMCA. To establish links with other user involvement/carer and advocacy groups.

These and ongoing action to be included in action plan (appendix 3) which is reviewed and monitored through the Learning Disabilities Steering Group.

6. Conclusion

People with learning disabilities have a right to the same quality of healthcare and access to as those without learning disabilities; it has been identified that a number of actions have been undertaken to improve the experience of people with learning disabilities and their families particularly in relation to promoting awareness and implementation of reasonable adjustments. It is acknowledge that there is further work to further enhance the experience.

7. References/Bibliography

Care Quality Commission (2009). Indicators for Acute and Specialist Trusts – Access to healthcare for people with a learning disability. CQC:London. 19th June 2009.

Changing Our Lives (2011) Quality of Health Principles www.changingourlives.org

Department of Health (2013). Six Lives Progress Report on Healthcare for people with Learning Disabilities. DOH:London

Department of Health (2010). Six Lives Progress Report.DOH:London

Department of Health (2009). Valuing People Now: a new three-year strategy for people with learning disabilities – making it happen for everyone. DOH:London 19th January 2009.

Department of Health (2008). Healthcare for All. Report of the independent inquiry into access to healthcare for people with a learning disability. July 2008.

Department of Health (2001). Valuing People. DOH:London.

Heslop et all (2013). Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Learning Disabilities Observatory.

MENCAP (2012) Death by Indifference: 74 deaths and counting. A progress report 5 years on

MENCAP (2007) Death by Indifference.

Ombudsman (2009). Six Lives: the provision of public services to people with learning disabilities, 23rd March 2009.

Appendix 1 Case Study Ruth White Learning Disabilities Acute Liasion Nurse

A real life story where the MCA a BIM and reasonable adjustments have been used to support successful outcomes in the acute sector.

Individual "A" is a 46 year old male with severe learning disability and ASD. He lives in a residential home with 24 hour support. Home informed us that a referral had been made to gastroenterology department by the GP following change individuals behaviour and signs and symptoms of gastro pain. Individual A had a history of non compliance with medical interventions and challenging behaviours.

Acute liaison contacted the gastroenterology department to ensure that reasonable adjustments were made for OPA, he was given the first double appointment of the day to prevent waiting times and Acute liaison supported. Once the individual had been allocated a consultant the acute liaison team emailed them to ensure they were aware of his learning disability and potential complexities with capacity.

Prior to the OPA a home visit was carried out to support with completion of the health passport and to confirm arrangements of the appointment, home confirmed that Individual "A" had active involvement from his mother who was attending the OPA therefore capacity and BI could be addressed on the day.

On the day of the OPA Individual "A" was met by us and supported through the hospital and outpatients department with minimal waiting. The consultant requested endoscopy and ultrasound with the suspicion of gallbladder issues. A capacity assessment was completed at the appointment by the consultant with the support and guidance from AL and BI decision made that Individual "A" required the investigations. A Discussion was than had regarding compliance and reasonable adjustment that could be made to ensure that the investigations were successful. Plan was as follows:

- Individual to visit the ward area and be given pictorial information and prompts before the investigation to ensure he is less anxious on the day
- Both procedures to be carried out on the same day to prevent the distress of two admissions and sedation being given twice.
- Reduced waiting times on the day to prevent further distress
- Pre- med to be administered in the community prior to admission to reduce anxieties,(This was arrange with AL in partnership with consultant psychiatrist)
- Oral midazolam to be given on the day as sedation. It was agreed that this was least restrictive option as appose to GA and previous investigation had been successful with this approach).

BI decision and paperwork was completed on the day to ensure that there is no delay in investigation.

Prior to the procedure work was carried out in the community and liaising with UHCW to ensure that all elements of the plan were completed. AL also met with individual "A" and carers on the day to support the plan.

Outcome for the individual was that the investigations were successful which led to a diagnosis of small gallstones. It was felt at this time that this could be managed through medication and diet. The referral was then followed up in the community to monitor and ensure that that staff felt educated and supported to manage the changes. Individual "A's" behaviours have now reduced and he appears to be in much less pain. He continues to remain open to the gastro team for a follow up appointment.

Appendix 2 – 5 things in 5 minutes

Your patient also has a learning disability... it will help them if you take just 5 minutes to consider these 5 things...



Values and misconceptions...

... Your patient probably enjoys life, has hobbies, friends, nieces or nephews, may like to go out, etc. He or she will have hopes, fears and dreams just like you. People with a learning disability experience pain and suffering just like you. Check out their

Carers...

... Where communication is tricky, carers are usually the experts about a person with a learning disability. They may be paid carers, or family. A carer will be able to understand what he or she needs and wants, they will know what frightens them or cheers them up, if there is something wrong and if the person is not well. Listen to them, use their expertise, involve them and look after them. Consider if extra support may need to be required.

Capacity and Consent

It should never be assumed that capacity to consent is absent—the Form for adults unable to consent should be used and all relevant information to undertake capacity assessment is available on the intranet or by contacting the Learning disability Liaison team.

4

Communication...

Can be difficult for most people with a learning disability. Use simple language, short sentences with 1 key idea. Pause between sentences. Give them time to think and respond. Check they have understood. Be creative - support what you are saying by using gesture, demonstrating, pictures, etc. Utilising the Picto com book. Remember too the HOSPITAL PASSPORT ... is a valuable source of good information about this person. It is their property and should remain in their bed space so everyone can read it.

5

Reasonable adjustments (being flexible)...

... It is the law that services should make 'reasonable adjustments' to ensure people with a disability can get equal outcomes. Reasonable adjustments are usually very easy to make, but just need a moment's thought from you. Ask yourself 'How could I make this easier / possible for this person. Record what you have done, go on, why not boast about it!!

Appendix 3 – Action Plan

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Theme	Actions required	By whom	Time frame	Progress Green - achieved, Orange - in progress Yellow- not yet commenced Red – Delay in progress
<u>Accessible</u> <u>information for</u> <u>patients</u> families and carers:	Determine progress with accessible complaints, liaise with complaints dept identify actions required	RW SOB KM	One month	Current complaints form being reviewed by - Key Worker from Grapevine L D charity following this meeting to be arranged with Sharon Wyman
	Identify method of gaining meaningful feedback from LD patients	RW SOB	Two months	Met with Patient Involvement facilitator- Impressions is not currently being updated- meeting organised to identify any other ways
a. Complaints b. Feedback c. Information	Accessible information to be collated and inputted onto LD intranet, this includes information sheets and links to the LD toolkit	RW SOB KM	TBC by ADC	Information submitted for insertion
<u>Staff education</u> a Preceptorship,ECP and Pre-registration students	Continue to provide training to these staff groups- adjust content based on feedback	RW SOB KM	On going	Content adjusted based on feedback to include more information on what a learning disability is
b AHP/medics/medical student training	Obtain training records and input onto OLM	KM EB	One month	Since 2011 Qualified staff & AHP's 7 HCSW- 781 Students-327
c Face to face training of Nursing staff and HCSW	Identify lead for AHP/Medics/Medical student training and negotiate input (ensure training records obtained)	KM, RW	6 months	SALT and dietician training undertaken, now liaising with physiotherapists and volunteers
	Prepare basic training session for day room delivery- include what is LD plus 5 key areas:-Best interest-IMCA-MCA-CONSENT- CONTACTS	RW SOB KM	One month	Power training – five key points prepared to deliver in 5 minutes Values and misconceptions Carers Capacity and Consent Communication Reasonable adjustments (being flexible)
	Undertake training trust wide targeting initially on key areas identified from previous audits	RW SOB KM	On going	Training commenced Trust wide every Tues afternoons dedicated to power training
	Plan week to coincide with MENCAPS L/D week 2013 (Rugby St Cross) will have full day dedicated 1 st October 2013)	RW KM SOB	One month	Activities for LD week planned and flyer produced and circulated to Matrons, ward managers, AHP leads Junior doctor leads, volunteers
	Grapevine sessions in CSB for ALL staff include reception, admin AHP nurses medics volunteers blaster	RW KM	2 weeks	Three interactive sessions organised throughout LD week- sessions provided by Grapevine- a learning disability charity – with role play from actors with an LD, question and answer quizzes, and a session by the Trusts Acute Liaison Nurse

				for LD
	Stands in the fover	RW SOB	2weeks	Partly manned boards in fover (manned by LD team and Grapevine)
	Intranet messages	KM	2 weeks	Communications have displayed advertising flyer commencing 5 th August to advertise planned events for the week
UHCW link network	Revise Format of 'Link worker' meetings based on poor attendance	KM SOB RW	2 weeks	LD steering group meeting- agreed that LD 'champions' will be recruited one or two full day study days per year to include comprehensive sessions from internal and external contacts ie Grapevine, specialist LD nurses etc
	Gain feedback on interest in bi yearly LD 'Ambassador' days or Champions mentioned above	RW KM, SOB	1 month	Positive feedback received- sessions to be planned for start of 2014-
	Prepare sessions based on feedback and deliver	RW SOB KM	4 months	In progress
Cross Boundary Information Sharing	Liaise with key trust personnel to facilitate relevant information exchange as current system is based on old data.	KM GA RW SOB	2 months	Meeting with ict- Principle systems operations manager- who will co-ordinate negotiations between the Partnership Trust and UHCW to obtain regular updated information. Contact made monthly for updates
	Apply for CRRS alert (Trust flagging system) for LD patients	KM GA RW SOB	9 th October 2013	Meeting undertaken with health records leadwho sits on the Information Governance Committee Alerts Sub-group (IGCAS) and guidance received for application, LD team and Practice Facilitator booked on to attend approval committee 9 th October 2013
Learning Disability Audit	Agree format and date for 2013 audit based on National agendas and Trust priorities	RW,KM,SOB		Meetings planned to discuss 2013 audit format and agree date to undertake it 19 th and 23 rd September 2012
	Undertake audit	KM RW SOB	3 month	
	Produce report based on results	KM RW SOB	6 months	
	Disseminate results at key forums (ward managers, matrons)	RW KM SOB	6 months	
	Base 2014 action plan on 2013 audit results	RW KM SOB	6 months	
Capacity and	Multiagency, multi disciplinary review of consent form 4	KM AP	6 months	New form completed and agreed at Trust Clinical Business Records
Consent	Organise printing of new form in liaison with Deputy Medical director and EPR scanning lead	KM AP	2 months	Forms currently in printing
	Assist in roll out plan for 'new ' form	KM AP MP	1 month	Awaiting printing completion
	Educate and inform staff- (nursing) at ward managers/matrons, during power training, at specialist nurse meetings	KM RW SOB		Awaiting printing completion
	Educate and inform staff (medics)	MP AP		Awaiting printing completion
LD Guidelines and care bundle	Produce Trustwide LD guidelines to include generic patient pathway	RW KM SOB	1 month	Draft guidelines completed awaiting review by LD steering group
	Produce 'care bundle' based on 5 key messages above	KM RW SOB	2 months	In progress awaiting 5 key messages logo.