Improving dignity, care, experiences and outcomes

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Getting better in hospital?

- People with a learning disability experience more admissions to hospital (26%) compared to the general population (14%) (Mencap 2004). Yet, ‘the quality of care in the NHS and social services for people with learning disabilities is at best patchy, and at worst an indictment of our society’. (Parliamentary and Health Ombudsman 2009)
This talk

• My work
• Reasonable adjustments
• Hospital Passport
• Ensuring dignity, patient safety and improved outcomes
• Involvement
• What we can all do
Service Weaknesses & Poor Attitudes

- **Neglect, Abuse, Poor Training & management of services** *(HC (2006) (2007))*
- ‘**Complacency and a lazy fatalism**’ *(DRC(2006))*
- **People with learning disabilities ‘just do’ die younger** *(DRC(2006))*
- **People with learning disabilities ‘just wont’ look after their health needs or turn up for appointments** *(DRC(2006))*
- **People with learning disabilities less likely to be given some of the significant evidence-based treatments and health checks** *(DRC(2006))*
- **Death by indifference** *(Mencap(2007))*
‘The extent to which the rights of adults with learning disabilities are being respected raises fundamental issues of humanity, dignity, equality, respect and autonomy….. Taking a positive and proactive approach to the creation of a culture of human rights will encourage a move away from negative attitudes and stereotypes”

Joint Committee on Human Rights (2008p5.)
‘Health service staff, particularly those working in general healthcare, have very limited knowledge about learning disability. They are unfamiliar with the legislative framework, and commonly fail to understand that a right to equal treatment does not mean treatment should be the same.’ Independent Inquiry into Access to Healthcare for People with Learning Disabilities (2008, p. 7).
My Role

• My Role 60% Consultant Nurse LD (3 days per week)
• 40% Senior Lecturer LD (2 days per week)
My Role

• Leadership, Accountability, Responsibility
• Embed systematic change e.g reasonable adjustments
• Admission and discharge – e.g. JS
• Assessing capacity
• Ensure safe lawful practice
• Improving health outcomes
• Leading research and guidance developments
• Educating and supporting ALL hospital staff and students to get it right for people with a learning disability
• Working together with people with a learning disability, families, carers, community and hospital based staff
Role of Consultant Nurse Learning Disabilities at St. George’s

- **Assessing and addressing issues** e.g. consent, unhappy family members, complaints, communication difficulties and finding solutions
- **Protecting beds in advance of admission** enabling an improved service to the person, their family/carer. Ensuring that staff on wards are aware of the person needs prior to admission
- **Enabling community clinicians to directly assist in the care and treatment of a person with a learning disability in hospital**
- **Being a central point of expert advice, 2nd opinion, referral and support** as well as service innovations
Reasonable Adjustments

• The first or last appointment
• A double appointment
• Food and drink for family / carers
• No fixed visiting times
• A bed and or chair for a family member / carer
• A hospital passport
• Accessible information – communication book
• Care that involves the person with a learning disability and their families/carers
Reasonable Adjustments

• 1:1 Support for person
• Altering environment
• Ensuring safe discharges
• Signing, photos, fewer words
• Equipment
• Protect beds in advance of admission
• Education of staff at all levels
• Hospital Passport
DIGNITY  ‘The nurses and doctors know how to help me because of the passport’ John

Jim Blair and John O’Neil, who helped develop the passport
Hospital Passport

This is my Hospital Passport

For people with learning disabilities coming to St. George’s Hospital

My name is:

If I have to go to hospital this book needs to go with me. It gives hospital staff important information about me.

It needs to hang on the end of my bed and a copy should be put in my notes.

Nursing and medical staff please look at my passport before you do any interventions with me.

Things you must know about me

Name:
Likes to be known as:
Date of Birth:
Address:
Tel No:

How I communicate/What language I speak:

Family contact person:
Relationship e.g. Mum, Dad:
Tel No:

Person that gives me most support:

Religion:
Religious needs:
Ethnicity:

My carer speaks:

Level of support (who needs to stay and how often):

This passport belongs to me. Please return it when I am discharged.
The hospital passport
adapted from Gloucestershire NHS PCT

• Things **you must** know about me

• Things that are **important** to me

• My **likes** and **dislikes**

• For a copy visit  [http://www.easyhealth.org.uk/hospitals.aspx](http://www.easyhealth.org.uk/hospitals.aspx)
How the passport changes care

- Filled in by people with learning disabilities and their supporter’s
- Provides a complete view of the person
- Not just about ill health
- Owned by the individual
- Personalises and dignifies care
- Enhances patient safety by providing information about a person who may not otherwise be able to tell health professionals
How they have changed care

• People are seen as being more involved in their care
• Personalised and dignified care
• Enabling a person to acquire a bed in a rehab hospital
• Change in care directly because of what was written
Ensuring dignity

- Anna, a 45 year old woman with Down Syndrome was admitted to a ward because of pneumonia. Staff found out from the passport that she is frightened of the dark and so ensured that she had a bedside light by her at night. They also found out that she likes Elvis Presley and so prior to any procedures, for example, blood pressure monitoring, they would talk to her about Elvis.

- This example demonstrates how by making small personalised adjustments, often at no financial cost, anything to enhance an individual’s dignity and quality of care can be beneficial.
Ensuring patient safety - *Case examples*

- Alice* has severe learning disabilities and her passport said she is allergic to eggs. So the ward sister, having read this, contacted the person’s residential home to find out if it was a serious reaction causing respiratory problems or a less dangerous rash.

- Mahendra* was told he could not eat or drink for a set period of time after a doctor had read in his passport that he bubbles up liquids and regurgitates food. This could indicate a severe swallowing problem known as dysphagia, which can lead to choking.

- These issues may not have been picked up if the passport had not been completed.
Improving patient safety

• Ensuring that the service is flexible
• Educating health professionals working with a person with a learning disability about that person’s specific needs
• Understanding that family members and carers provide emotional and advocacy support for the person with a learning disability
• Providing reasonable adjustments
Improving patient safety

• Communicating with the person with a learning disability using a range of tools such as photographs, symbols and jargon free language

• Emphasising that every person’s life has worth

• Working together with the person, their family/carer, community health and social care colleagues

• Blocking unsafe discharges - a person might be medically fit but their discharge would not be considered safe
Improving patient safety

- **Clearer discharges** create systems and structures to ensure that discharge information is clear, free from jargon.
- **Learning disability issues and patient numbers should be raised at every safeguarding board meeting**
- **Access to acute local networks** – to create cross service policies / guidance
- **Hospital, primary and community clinicians to be actively engaged in the local Learning Disability Partnership Boards**
• LD Our Health Our Hospital
Being involved - **Learning Disability Panel**

**LD Our Health, Our Hospital**

- Set up in March 2010 to hold the consultant nurse to account.
- Include 4 people with a learning disability, 3 parents, 2 or 3 people from local Charities, 2 or 3 people from the Hospital
- Meet every 4 months.
Being involved **LD Our Health Our Hospital**

- **Improve the hospital** - people getting more help in hospital
- **Know about what has been happening in hospital** - hear from Consultant Nurse about the work at St.George’s and ask questions
- **Talk about how to make changes and make things better**
- **Share comments about things that have gone well or not**
- **Talk about what staff in the hospital need to know**
- **Improve accessible information**
- **Be ‘observers’ (mystery shoppers) in the hospital**
- **Influence changes**
- **Invite hospital staff to talk to the panel**
Learning Disability Open Meeting

- **Opportunities, Partnerships, Educating and Networking**

- created in 2002 for a range of practitioners to share knowledge & experiences with each other and people with intellectual disabilities and their carers. 25-45 people attend each of 5-8 meetings a year.

- led to the development of service user, carer & inter-professional partnerships in terms of practice, education & service delivery.
LD Caring Solutions

• Set up September 2006 - enable parents to share concerns, identify priorities and to form collaborative partnerships with education, health and social care service providers to influence change.
• Drives services forward in partnership with service providers in an action focused manner.
• 18 parents, representing a range of children and adults aged from 6 to 56 with learning disabilities and complex needs.
• Meeting with local Commissioners
• Advising National Institute for Health and Clinical Excellence (NICE), Nursing and Midwifery Council, London Network of Learning Disability Nurses, Royal College of Nursing, Commissioner for Carers, The Healthcare Commission and Valuing People Now
• Training the health and social care professionals of tomorrow
• Guiding developments in hospital care
What health professionals need to have

- Sound clinical, legal and emotional knowledge, skills, attitudes and values
- Skills to lead, innovate, support, educate, link, advocate, challenge
- Confident, comfortable and competent in a variety of service configurations
- Skills to use and undertake research to improve lives
- Flexible
Be involved, ensure dignity and improve care

Involve people with learning disabilities and their families/carers =

• Hospital Passports
• Consultations, Care, treatment and discharges
• Fewer words more pictures
• Access committee
• Employ people with learning disabilities within organisations
• Educating professionals
• Developing services
• Evaluating care
• Research
• BE INVOLVED SHAPE SERVICES
See the person experience their qualities
• Winterbourne View
  2011 = still *much* to do
• “It is no use saying, ‘We are doing our best’ You have got to succeed in doing what is necessary.”

•  Winston Churchill
Athletes gain a significant sense of worth through competing, socialising and achieving personal dreams and ambitions that can not be easily met through other means.
Learning About Intellectual Disabilities and Health

Whatever the question, if it’s about learning disability then www.intellectualdisability.info probably has the answer

www.intellectualdisability.info
Online accessible health information for people with learning disabilities

www.easyhealth.org.uk