

Meeting the Requirements of Equality Legislation

A Fairer NHS Greater Glasgow & Clyde 2013 – 2016

Briefing Paper:
Learning Disability

June 2013

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Demographics / Health needs

People with learning disabilities have a significant and lifelong condition that started before adulthood and which affects their development.

This means people with learning disabilities need help to:

- understand information
- learn skills
- cope independently

However, this is only part of a description. A person with learning disability can be much more – a friend, a family member, a community activist, a student, a parent, an employee, an employer.

People with learning disabilities represent a diverse group and come from all backgrounds, cultures and walks of life. There are more boys and men with learning disabilities than girls and women, although at older ages gender distribution is more equal as women typically live longer.

The number of adults with learning disabilities known to social services within Greater Glasgow and Clyde is 6018 (Same As You statistical return 2006). From August 2012 the Learning Disability Local Enhanced Service (LD LES) register held approximately 5,400 adults with learning disabilities registered with GP's within NHSGGC.

The 2012 – 2014 LD LES requires GP Practices to identify and record the severity of children (under age 16) with learning disabilities. This is due to less accurate figures for children with a learning disability in NHSGGC than for the adult population.

Children and young people figures are based on school census data on learning disability which predicts approx 20 per 1000 pupils have a learning disability. This additional requirement of the LD LES to record children who have a learning disability will begin to identify the future needs for service planning.

Health needs of people with a Learning Disability

People with Learning Disability:

- Have poorer health than any other group in Scotland (NHS Scotland, (2004) People with learning disabilities in Scotland - HNA report)
- Die younger than the general population (On average 13 or 20 years younger - men and women respectively – and of preventable causes (Confidential Inquiry of Premature Deaths of People with a Learning Disability, (CIPOLD), 2013)
- Have differing causes of death, which are respiratory illness, cardiovascular disease (linked to congenital heart defects) and gut cancers, compared with lung cancer, heart disease and strokes in the Scottish Population. (CIPOLD, 2013)
- Have more physical and mental health problems. Many of the causes of learning disability can lead to physical and mental ill health.
- Are significantly more likely to have epilepsy – 25% compared with 1% of general population. Their seizure types are often different and are managed on a complex regimen of medication.
- Are more likely to have Mental Health problems, (40-50% of learning disability population, compared with 1-10% of general population), with differing presentation of symptoms.
- On average, have 5 co-morbidities (long term health condition), compared with 1 or 2 in the general population. (CIPOLD, 2013). As a consequence people with learning disability are often on many medications.
- Are more likely to have sensory impairments – approximately 60% will have visual problems and 40% hearing difficulties.
- Are significantly more likely to be underweight (especially with increased severity of learning disability) or obese (especially in those with mild/moderate learning disability), than the general population.
- Are less likely to eat healthily or exercise than the general population. They may not have the knowledge or understanding to make healthier choices and often rely on others for support and communication. This is further complicated by inaccessible services.
- Are more likely to be exposed to poverty, poor housing and experience lack of employment, social isolation and discrimination, lifelong exclusion resulting from lack of choice and opportunity as well as experiencing significant barriers to access services. These are experienced regardless of where a person lives and not only in areas of social deprivation.
- Are less likely to be smokers or drink alcohol, however those who do find prevention and cessation programmes are difficult to access.
- More people with a learning disability have experienced bullying and harassment or have been abused due to their vulnerability.

Patient experience

Edward's experience

Edward complained about the treatment he received in a hospital in NHS GGC. As a result, he shared his experience and worked with senior nurses to develop a DVD learning and education resource to be used for staff training. This resource reinforces the importance of person-centred care. As a recognition of his work with NHS GGC he was awarded Patient Ambassador in the 2012 Chairman's awards.

In Scotland there have been a number of fatal accident inquiries (FAI) which have highlighted significant barriers and risks many people with a learning disability face when using general health services. Most report on issues relating to communication, differential diagnosis, under-nutrition and attitudes of staff. These mirror the findings of the recent Confidential Inquiry into Deaths of People with a Learning Disability, and of the reports by Mencap.

Other reports of patient experience include:

Confidential Inquiry into the Premature Deaths of people with Learning Disabilities, 2013 - this reports on the causes of death of people with a learning disability and how they differ to the general population by being earlier and often preventable and of different causes leading to death (eg pneumonia, underweight).

Death By Indifference 74 deaths and counting – is a follow up of the Mencap Death by Indifference report and the 'Getting it right' campaign.

Death by Indifference – Mencap 2007 - case studies of discrimination in hospitals for people with learning disability resulting in their death.

Experience of discrimination

Bullying and harassment

It has been reported that 90% of people with a learning disability have experienced bullying or harassment due to their learning disability. 66% are regularly bullied or harassed, with 32% experiencing this daily. (Papworth trust 2012 and Living in Fear, 1999 – Mencap report)

Poverty

Papworth Trust report that 60% of children and young people with a learning disability live in poverty.

65% of people with a learning disability would like a job. In 2010/2011, 6.6% of people with a learning disability were in paid employment, the majority of whom worked less than 16 hours a week. This is significantly less than in the working age population (77.3%) and the Disabled population (47.4%) – Office for Disability Issues – DWP.

Barriers to access

People with learning disability experience barriers to access throughout the NHS:

- Communication – often we rely on written information for advice, appointments, signs and information. This is often not provided in an easily understood way.
- Physical access – not all NHS buildings are easy to access. Some buildings are old and not suitable for wheelchairs or those with poor mobility.
- Attitudes – some NHS staff have no experience of working with people with a learning disability or don't know how to communicate with people with a learning disability or are frightened of getting it wrong.
- Differential diagnosis – often a behaviour change is associated with a persons learning disability when the actual change in behaviour is due to physical ill health or a display of pain.

Sexual Health and Wellbeing

People with learning disability have historically had their sexual rights ignored. Often sexuality is only discussed when there is a problem. Coping with puberty, sexual identity and feelings can be difficult for people with a learning disability, who may struggle to understand emotions and changes to their body.

People with learning disability have told us that they want to learn about friendships and relationships, and include these in their care plans. They want information about sex, sexual health and relationships so that they are safer and more confident in accessing their communities.

Studies of adults with learning disabilities show a high levels of sexual abuse, with prevalence rates ranging from 61-83% for women and 25 -32% for men.

(McCarthy and Thompson, 1997, A Prevalence Study of Sexual Abuse of Adults with Intellectual Disabilities Referred for Sex Education, and Sobsey, 1994 Violence and Abuse in the Lives of People with Disabilities: the end of silent acceptance?)

People with learning disability from Black Minority Ethnic (BME) communities

There is an increased prevalence of severe learning disability in the UK South Asian communities. There are many suggestions why this may be the case which include, a higher incidence of first cousin marriages, barriers to access antenatal care and genetic screening for people from BME communities. It is reported that having a learning disability from BME communities leads to 'double discrimination' and as such they experience the poorest of health.

Multiple inequalities

People with learning disabilities can be gay, from a Black and Minority Ethnic Community, have mental health problems, have a physical disability and live in an area of social deprivation. The discrimination is then compound and complex and people who experience multiple inequality are further marginalised.

Resources

Key resources include:

- Keys to Life – Improving the quality of life for people with learning disabilities, (2013), Scottish Government
- Edward’s DVD – www.bespoken.me/video/listen-to-me-edward-s-story
- NHSGGC Hospital Information Booklet for Acute Hospital Admission
- Training from Learning Disability Liaison Team
- Public Health Resource Unit LD resource directory
- Health Education Scotland ‘Keep Yourself Healthy’ range of health information leaflets
- http://www.equalitiesinhealth.org/public_html/disability_support_resources.html

Training available in house

- Edward’s DVD (see above)
- Acute training, provided by Learning Disability Liaison Team, (LDLT) and Local Learning Disability Teams
- Primary Care training provided by LDLT
- An e learning module is being finalised and will be available on –
<http://www.staffnet.ggc.scot.nhs.uk/Human%20Resources/Learning%20and%20Education/E-Learning/Pages/E-Learning%20Homepage.aspx>

Involvement

The Corporate Inequalities Team has a Health Reference Group which meets regularly and includes members who have a learning disability.

People First Advocacy, Scottish Consortium for Learning Disability, the Good Life Group and Glasgow Good Information Group are existing groups of people with learning disabilities who have all been involved in some aspect of service change or planning within NHSGGC (for example Primary Care Communication Aid development, Acute Learning Disability Awareness training, Learning Disability service redesign).

Activity to address discrimination

Employment

Project Search, an employability model for young people with a learning disability is being introduced in Victoria Infirmary in 2013. 12 students will learn job skills within the facilities directorate through work placement rotations supported by job coaching and education partners.

Removing barriers to health care

Communication:

- NHSGGC Communication Support and Language Plan, and Accessible Information Policy and toolkit.
- Accessible Information Repository
- NHS photo library
- Equalities in Health website – www.equality.scot.nhs.uk
- Hospital Information booklet
- Primary Care Communication Aid for motivational interviewing
- GP Local Enhanced Service which requires GP practices to reduce barriers of access by offering flexible, longer appointments and provision of accessible health information with support for local learning disability and health improvement teams.

Attitudes:

- Training in Acute hospitals using Edward's experience DVD.

A 'Strategy for the Future' is NHSGGC's service redesign for all Learning Disability specialist services. It aims to create a society where people with a learning disability have: equal and active citizenship within society; control over personal outcomes; good and improved health and wellbeing and are safe and feel safe.

It hopes to achieve these by ensuring that specialist learning disability services are designed to enable mainstream services to deliver responsive and appropriate healthcare and provide specialist support when required. The service redesign will ensure the specialist learning disability workforce is equipped to provide this facilitation role.

The recent launch of 'Keys to Life' Scottish Government Policy on improving the quality of life for people with learning disabilities asserts the same aims as the NHSGGC strategy and provides the framework in which to work towards.

Acknowledgement

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- 1. Age**
- 2. Asylum Seekers and Refugees**
- 3. Bowel Screening**
- 4. Gender Reassignment and Transgender**
- 5. Homelessness**
- 6. Inequalities Sensitive Practice**
- 7. Learning Disability**
- 8. Prisoners**
- 9. Roma and Gypsy Travellers**
- 10. Sensory Impairment**
- 11. Sexual Orientation**