IMPROVING ACCESS IN BREAST SCREENING FOR INDIVIDUALS WITH LEARNING DISABILITIES.

Elli Purser – Macmillan CNS Breast (Screening) ONEL BSS, Formerly BHRUT
DOH define a learning disability (LD) as a “significant reduced ability to understand new or complex information; to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood”.

Causes: an inherited condition (eg fragile X), chromosome abnormalities (eg Down’s syndrome, turner syndrome), complications during pregnancy / birth (hypoxia, premature, foetal alcohol syndrome), illness or injury affecting brain development (RTA, child abuse) (Mental health foundation).
• It is estimated that in England there are 905,000 adults (18+) with a LD (530,000 men and 375,000 women) (source: Mental Health foundation 2011).

• It is estimated that 2% of the general population has a LD but those known to LD services are much smaller and its estimated that many (up to 50%) are living within the family home (The improving health and lives LD observatory 2013).
Uptake in breast screening lower in women with LD (DOH white paper 2001).

In the most recent year for which we have figures (2015 to 2016) 51% of people with learning disabilities eligible for breast cancer screening had the test compared to 67% of eligible people without identified learning disabilities (PHE, May 2018).

Back in 2013/4 CNS's felt we “could do more” to make screening more accessible for women with a LD.

Often felt “rushed” - LD clients require more time to process information.
PREVIOUS PRACTICE...

• Not identified….

Often not flagged to us when a LD client will be attending either routine mammo or second stage assessment. Collection of core demographic data is compromised by some screening and national IT systems (PHE Inequalities strategy March 2018) – Some GP’s more consistent with inputting onto register than others.

There are a large proportion of individuals who may have an undiagnosed LD who are unknown to agencies.
PREVIOUS PRACTICE...

• Limited liaison

Limited liaison between screening service and other agencies – ie GP’s, community LD nurses, care homes / assisted accommodation, carers etc.

Impetus for change….Made contact with community LD nurses - train the trainer BCC study day – organised for LD community nurses.
• Connolly (2013) cites three key themes regarding barriers to breast screening: scarcity of information, fear of medical intervention and embarrassment.

• LD clients are fearful of alien environment, unfamiliar faces and equipment, break from routine, being rushed and need to feel prepared (as per our liaison with LD community nurses – well women group).

• Our challenge was to try to address the above by making adjustments to our service alongside tailoring our information specifically for our LD client group.
WHAT WE DID...

• Could do better....

• We offer:
  • Mini tours, mammo at breast unit, book double slots for all appts, health promotion sessions, LD friendly / easy read info.
  • Reviewed BCC LD info (well woman LD group – service user involvement)
  • LD breast screening pathway.
WHAT WE DID…..

• Not identified...
• Encouragement of radiographer, GP’s, LD nurses, care home managers to flag LD client (when going for routine screening)
• National invitation letter.
• Better accessibility = more likely to return in future.
WHAT WE DID....

• Limited liaison....
• Forged links with community LD nurses, care home managers, hospital LD CNS.
• Gave talks at day centres re: breast awareness and screening – visual aids.
• Wrote to GP’s and LD community teams re: adjustments to service.
MEASURABILITY?....

• Problem! – large proportion of screening LD women unidentified (undiagnosed and unrecorded anyhow) therefore difficult to measure if uptake increased locally.

• Anecdotely still relatively small numbers of LD women coming through to second stage assessment – ? Because not coming for screening in first place.
WHAT WE DID / WHAT CAN WE DO?

• National invitation letter & leaflet (PHE)

• GP’s to ? Incorporate breast awareness / screening info into annual LD health check.

• LD community well woman groups.

• BCN tailored talks to LD audiences and carers.

• Time! – like with any woman - make the experience a good one to promote return!

• Liaison – pre, during and post assessment (and Ongoing referral – hospital passport)
About this pack
We want to help people with learning disabilities feel safe and confident about checking their breasts, and to seek help early if they are worried.

The pack includes:
- a book for people with learning disabilities
- a guide for supporters.

Cardiff People First

Thanks to Cardiff People First for their help with the original development of these resources.

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Breast screening

An easy guide about a health test for women aged 50 and over