

Background

Adult women with learning difficulties (ALD) face challenges accessing routine health care including reproductive, post reproductive healthcare and sexual health. Barriers related to disability make finding an appropriate reproductive healthcare needs difficult.

They may face difficulties with range of cognitive based tasks related to :
- conceptual understanding
- social and practical skills

Impact on their daily life depends on :
- severity of intellectual disability
- resources
- education
- support available

Challenges

Menstrual problems may be experienced more negatively by ALD women and management is challenging.

There may be concerns around :
- menstrual hygiene
- vulnerability to exploitation
- cyclical behaviour change
- pregnancy

Menopause is usually earlier in ALD women and earlier still for those with Down's syndrome.

Women with learning disabilities have similar physiological experiences, including hot flushes and night sweats, but difficulties in understanding and communication means additional support is often required.

Carers are often poorly trained and resourced to help these women understand the menopause. They may miss these menopause symptoms and may have difficulty in understanding if the physical and psychological problems are from menopausal changes or due to other causes.

Epilepsy is common in people with learning disabilities. Women with **catamenial epilepsy** (where seizure frequency is related to the menstrual cycle) might experience an increase in seizure frequency in perimenopause and decrease after menopause.

Evidence shows **cervical screening uptake is lower** in people with learning difficulties compared to the general population.

Objectives

At our reproductive healthcare hub at Oxleas NHS Foundation Trust -a multi-disciplinary (MDT) setting, we provide holistic care with teams including Gynaecology, Sexual and Reproductive health (SRH), Learning difficulties, Mental health team and Auxiliary services.

We manage ALD for :
- menstrual problems
- cervical smear
- routine STI screen
- routine support for reproductive well being
- contraceptive need assessment
- menopause management

Design

We planned to address this through creation of reproductive health easy read leaflets for ALD aiming to improving understanding of gynaecology and SRH issues and access. We aimed to reduce need for multiple appointments making the service efficient.

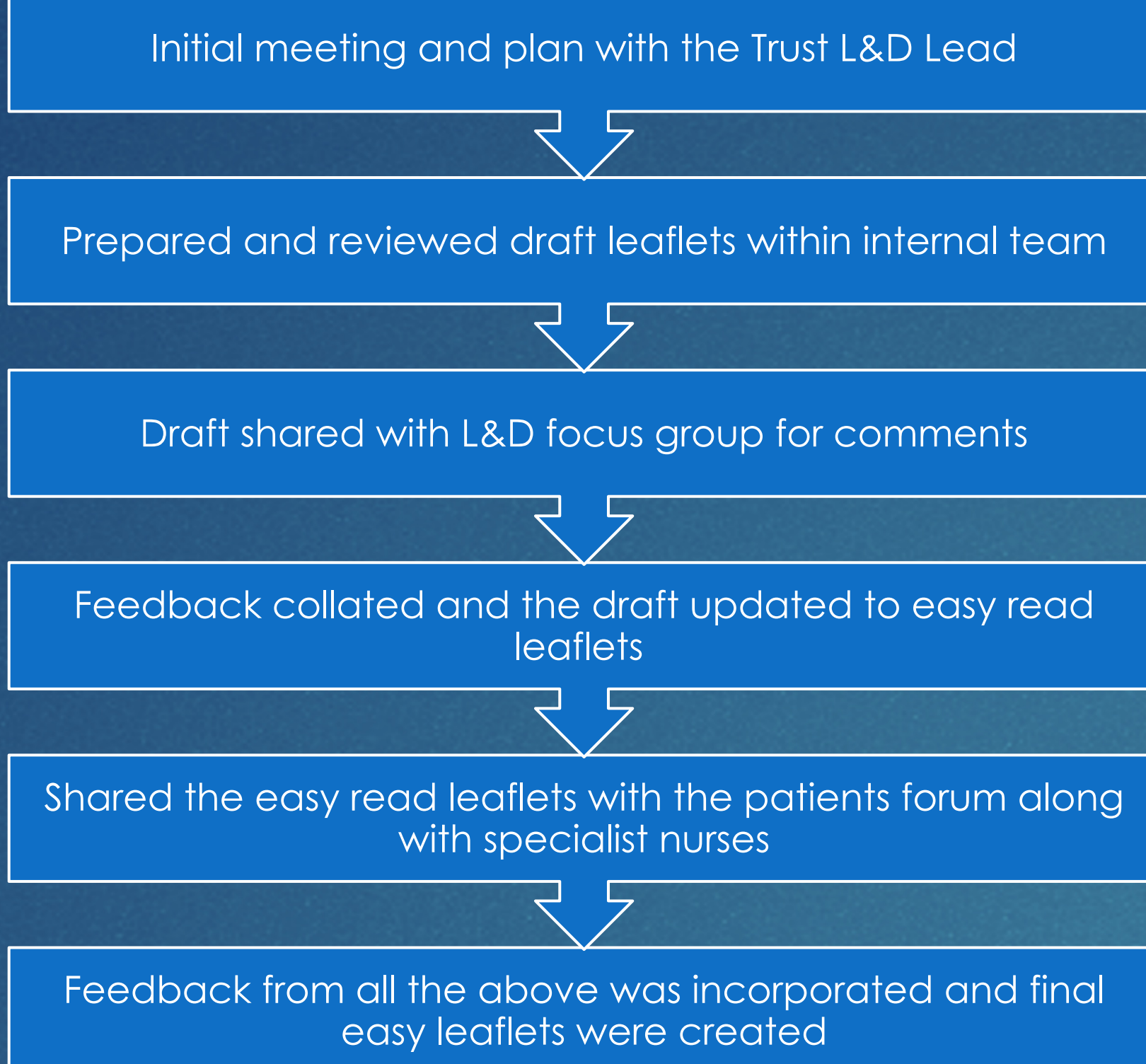
Methods

Important to make the information easily accessible and understandable for people with learning disabilities.

Visual guides and cues to aid communication is important to have a greater understanding of what is being conveyed.

We devised some easy read leaflets in conjunction with the ALD team at Oxleas. These leaflets are sent prior to their appointment so that the key worker could assist them in reviewing the information.

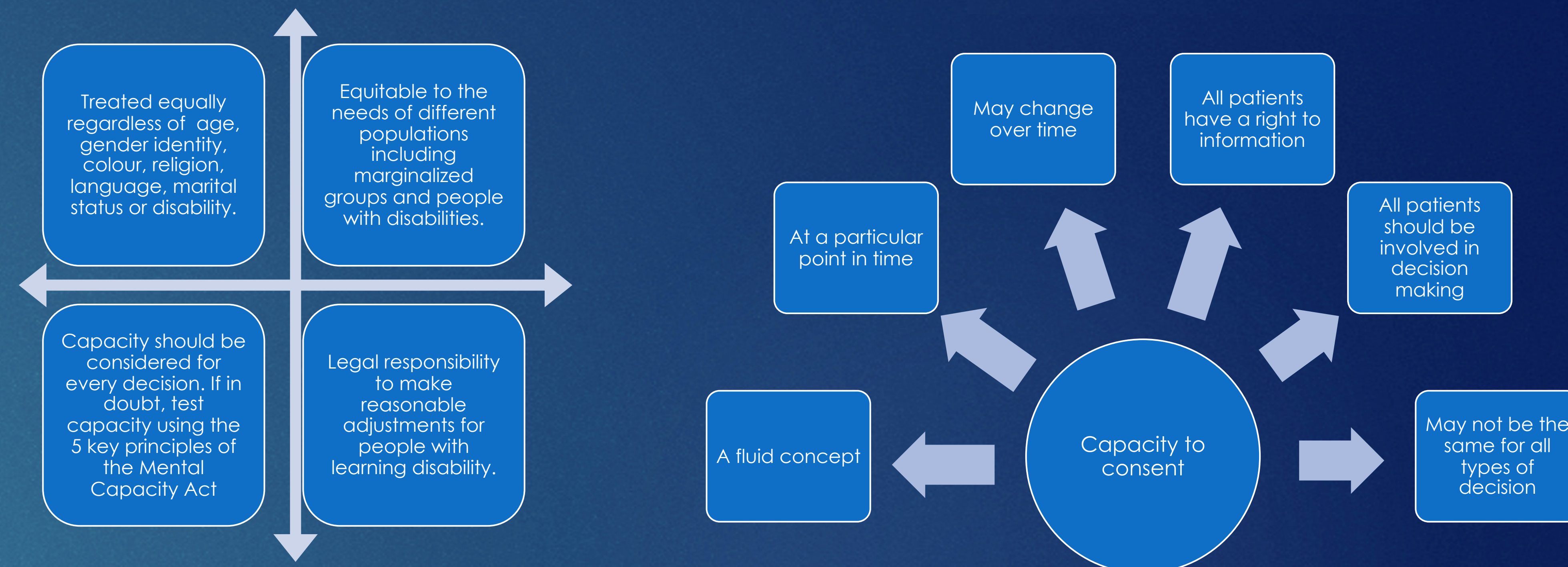
The process - How did we go about preparing the information leaflets



Special Considerations for Leaflet

- Simple English
- Short sentences
- Larger font size
- Bullet points
- Photos of equipment/machines used
- Colour photographs/symbols to support our words
 - Not too much colour also as that makes reading harder for some individuals
- Inclusive - Photo/picture representing ethnic minority groups as well

Sexual and Reproductive health rights : Counselling principles



Results

Working in an MDT team, we have great understanding of the wider team members' roles and boundaries. We understand responsibility and accountability in decision making and delegation.

We devised easy read leaflets on reproductive healthcare topics like Periods, peri-menopause, HRT, Pelvic scan, Mirena fitting, contraceptive pills, injection and implants etc. First page of some leaflets below :

Easy read information about periods

Having a period
As a girl becomes a woman her body changes.
This is called puberty.

One of these changes is having periods.

When a girl has her first period it can be a bit scary. It is nothing to worry about. It is a way that the body changes.

Periods can start at any time. Mainly from the age of 11 years to 15 years. See a doctor if your period has not started by 16 years old.

Why do periods happen?

Women have a womb (uterus) and ovaries in the lower part of their tummy.

The ovaries contain thousands of eggs.

Every month one egg will leave the ovary. This is called ovulation.

Having a pelvic (trans vaginal) scan

You are invited to have a pelvic scan to find out what is causing your health problem like heavy painful period.

The scan will take pictures of your pelvic area.

The appointment will take about 20 minutes.

If you are having a period it is still ok to the pelvic scan.

What will happen when you come for your scan

When you arrive, you will be asked to go to the toilet and pass urine.

If you are using a tampon, you will need to remove it before the scan.

Having a Mirena coil fitted

During a period, the lining of the womb comes out of the vagina as blood.

You have been having heavy periods.

Your doctor has told you that having a Mirena coil will mean your periods will be lighter and less painful.

A Mirena coil looks like this.

You can take paracetamol or ibuprofen before you go for your appointment.

How having HRT (hormone replacement therapy) can help you during the menopause

During the menopause your body begins to change.
This is because the hormones in your body are changing.

Changes in the hormone levels can result in the following

- hot flushes
- your heart beating faster
- aches in arm and legs
- put on weight
- trouble sleeping
- forget things and/or not able to concentrate
- mood changes.

Having a smear test

Women have smear tests to make sure their cervix is health.

Your cervix is inside your vagina

A doctor or nurse will carry out your smear test.

If you have a male doctor or nurse you can ask for a female doctor or nurse to do your smear test.

You can ask someone you trust to go with you to your appointment

This person is called a chaperone

The doctor or nurse will ask you to take off your clothes below your waist.

They will cover your private area with some tissue.

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Informed Consent



Conclusion

Life course approach to cover all aspects of reproductive health for ALD is implemented in our reproductive healthcare hub

ALD women in our reproductive healthcare hub are able to make informed decision using these easy read leaflets

Feedback from the patients **positive**

- reviewed easy read leaflets with their key workers and found these simple to understand
- helped ALD women to understand what was expected in the consultation
- Improved patient outcomes and reduced appointment times