

Principles supporting antenatal screening and reproductive choice

In most developed countries, expectant parents are offered a range of tests in pregnancy designed to predict the likelihood of a baby being born with chromosomal conditions, such as Down's syndrome and physical conditions, such as spina bifida and heart defects. If a diagnosis of a condition is made, in many settings, a termination of pregnancy may be offered. This makes antenatal screening and diagnosis an ethically sensitive area of medicine which needs to be framed in a careful way. We need to make sure expectant parents can make their own informed decisions at all points and remain respectful to those living with screened for conditions and their families.

The following principles were produced in 2023 following a meeting convened by the national charity Antenatal Results and Choices (ARC). The participants aimed to define a set of principles which provide a framework to support the provision of antenatal screening and reproductive choice, while also respecting those living with screened for conditions.

The attendees included members of rare and genetic condition support organisations, academics, parents of children with learning disabilities and reproductive rights advocates.

1. The principle of personal informed choice for antenatal screening

We believe that expectant parents should be able to choose whether to have antenatal screening tests, and should be able to choose any next steps when they receive their results. This can be achieved by:

- i. Antenatal screening for genetic and physical conditions must be presented as optional. Expectant parents must know that there is no preferred decision; having or not having screening tests is a personal choice. It should also be made clear that screening tests can be for information purposes only.
- ii. NHS approved pre-test information must be provided and easily accessible to expectant parents to help inform their decision-making. It is essential that expectant parents understand the difference between screening and diagnostic tests. While screening tests can predict the likelihood of a condition, only a diagnostic test can give certainty.
- iii. There must be an opportunity to discuss testing options with a suitably trained health care professional to help expectant parents consider what is individually important to them.
- iv. All decisions must be equally supported and expectant parents reassured that they can change their mind about having tests along the screening and diagnostic pathway.

2. The principle of respect for people living with screened for and diagnosed conditions and their families

We believe it is important that termination of pregnancy is not seen as the inevitable outcome if a diagnosis is made. This can be achieved by:

- i. Information on screened for or diagnosed conditions must be evidence-based, up-to-date and include both medical facts and descriptions of how life might be for those living with the condition and their families. This information should be informed by those with a broad range of lived experience.
- ii. While termination of pregnancy might be offered as an option after a prenatal diagnosis, care should be taken to ensure that expectant parents know that the choice about continuing or ending the pregnancy is theirs and no one option is preferred by their health care team*.
- iii. Screening tests should never be presented as first steps to potentially ending a pregnancy as screening can provide information that may help expectant parents prepare for a baby with a particular condition and optimise care during pregnancy, birth and immediately after the birth.

3. The principle of an educated and equipped workforce

We believe health care professionals must be trained and supported to provide individualised care through antenatal screening and its consequences and help expectant parents make their own informed decisions. To achieve this:

- i. All health care staff involved in antenatal screening, diagnosis and its consequences need high quality education in relation to delivery of screening programmes and informed choice. Training in communication skills to provide individualised care to expectant parents is essential and should include how to sensitively deliver unexpected or difficult news and support decision-making.
- ii. Staff who will discuss genetic or structural conditions must ensure that they are educated about the broad range of life experiences of families and individuals with these conditions and the full range of possible outcomes. They must know where to signpost expectant parents for more information. They should acknowledge uncertainties around future outcomes and how this may impact on parent decision-making.
- iii. All stages of the antenatal screening pathway should be carefully co-ordinated whatever decisions parents make. All staff must understand the pathways, the possible consequences of each decision point, and understand their role and responsibilities at all stages.

iv. Working with expectant parents through antenatal screening, diagnosis and its consequences can be professionally and personally challenging. Effective supervision that recognises the emotional impact should be in place for staff.

4. The principle of reproductive choice

We believe that all expectant parents must be able to make the decisions about their pregnancy that are individually right for them. To achieve this:

- i. The decision to continue a pregnancy or not after a diagnosis or finding is personal to the pregnant individual and must be respected as such.
- ii. Terminating a pregnancy because of potential disability is not discriminatory to disabled people under the Equality Act 2010. Only once a person is born are they afforded legal rights under the Equality Act. There is no inherent conflict in supporting informed choice and supporting the rights of disabled people.
- iii. Reproductive choice extends to all expectant parents regardless of disability. Disabled people have a right to make personal decisions about antenatal screening, diagnosis and termination of pregnancy.
- iv. The existing evidence is that neither prohibiting nor enabling reproductive choice improves the lives of disabled people.

5. The principle of an inclusive society

We believe we must all commit to creating a society that is inclusive of and meets the needs of disabled people. To achieve this:

- i. The lawful rights of disabled people must be fully respected. All must work to create a truly inclusive society in which disabled people can thrive. Disabled people are legally and morally entitled to have their needs met in education, health and social care, employment and in all aspects of their lives.
- ii. Expectant parents who are disabled must be treated equitably and their individual choices supported.
- iii. The humanity and intrinsic value of disabled people should not be compromised in order to make a case for supporting reproductive choice. There is no inherent conflict in supporting the rights of disabled people and supporting reproductive choice.

Further guidance: The seven principles of decision making and consent - professional standards
- GMC

*While conscientious objection to involvement in abortion provision is a legal right, care should be taken that this does not impede care for expectant parents considering or opting for termination.