

Prenatal screening – SDA

Should prenatal screening be accepted as a standard feature of reproductive healthcare?

For this project, I decided to focus on the topic of prenatal screening. My physical drawing of a 12 week old baby represents the period where a test for conditions such as Downs syndrome would usually take place. Surrounding the baby are various arrows, some of which are in favour of prenatal testing (Green) and others which are against it (Pink). This visual piece will enable me to present and evaluate the debate surrounding this topic, before arriving at my own personal recommendations and conclusions. Even though prenatal screening is widely used and will be for years to come, I will be assessing whether our attitudes should generally be geared towards accepting the merits and positive features of having a child no matter what. This line of thought is perhaps further enhanced through the womb in the picture representing a bubble which exists between the baby and the outside world which is brimming with topics of debate. The baby will ultimately have no say in regards to termination, and this piece will assess whether such a decision making process should be the norm.

When looking at this particular question, we must firstly consider the merits of prenatal screening and what it can provide to expecting parents. While this happens to be a personal choice with a number of complex factors, there appears to be an overarching fear that if the 'bad' news does arrive families and the children can both evidently struggle while they 'try to position their kids for some form of independence and still fail'¹. This anonymous blog post is from the perspective of someone who already had children, so it is evident from their perspective that the image of how a child should be and act could never be satisfied in the case of a disabled child. This feeling of the child 'suffering' or 'enduring a lifetime of pain' is shared by many individuals who go ahead with screening and subsequently choose to terminate. In Europe, around 92% of parents who are told their baby has a chromosomal condition will terminate their pregnancy². This large of a figure cannot just be attributed to emotional decisions such as pain, so other factors must also be considered. From a financial perspective, a study established that 'parents of disabled children spent

¹ Amy Julia Becker, 'I tested and I terminated and I do not regret by anonymous' (2013)

² <https://www.mamamia.com.au/terminate-down-syndrome-pregnancy/>

almost twice as much on comparable items (£65.51) as parents of non-disabled children (£31.22) per week³. This is likely to result in emotional costs and families adjusting to the needs of their child, which is a commitment that shouldn't be underestimated. In a recent women's march where attendees supported aborting Down syndrome babies, a special education teacher insisted that despite her personal opinions on the matter she would refuse to support any law 'that would get in the way of a woman's right to choose abortion'⁴. While it is important that this decision is not purely made by a legislator, it is equally important in my opinion that decisions consider a much wider scope of impact. This is what my physical piece looks to represent, as a complete acceptance of screening can be a very narrow and pessimistic mindset.

800,000 screenings take place in the UK annually. While this can be a result of a variety of different factors, it is evident that there is a very negative stigma surrounding conditions like Down syndrome. Friends and family in this situation sometimes present termination as the only consideration and there is a great deal of pressure applied on mothers. Sally Phillips, who was one of my main inspirations for choosing this drawing and the accompanying research question, made a very interesting point that 'money is not being utilised to improve the medical conditions of these children or integrate them better in school'⁵. While our attitudes are somewhat fixated on carrying out screening because the resources are readily available, it is important to consider whether we should invest more in making the other option of raising a disabled child a much more easier process by taking the steps to implement the necessary resources and support networks as well as providing useful incentives for parents. Support groups and workshops are an important aspect of this journey. A possible reason why these schemes haven't fully been initiated is because the opinions of people with experience of these conditions are underrepresented. In order to demonstrate this, I will temporarily be moving away from Down syndrome specifically to look at how serious conditions are viewed in general. Autosomal recessive conditions such as spinal muscular atrophy (SMA) are approached with population carrier screening being the main way of tackling them.

³ Barbara Dobson, Sue Middleton and Alan Beardsworth, 'The impact of childhood disability on family life' (2001)

⁴ Lisa Bourne, 'Women's march attendees explain why they support aborting Down syndrome babies'

⁵ Sally Phillips, 'Challenging misconceptions around Down's syndrome' (2016)

There is not much information however on the attitudes of the general public towards carrier screening and even less is known about the opinions of people living with these genetic conditions. The research carried out by Boardman et al⁶. brings up some insightful results, as 2 detailed surveys discovered that people with experience of type II SMA in some way, whether this be personal experience or being otherwise impacted by the condition through friends and family, were not likely to support pre-conception and prenatal carrier screening as opposed to people who did not have a prior experience with the condition. This study highlights the significance of prior experience with a condition to screening attitudes. It also brings attention to the need for good quality educational resources in relation to future screening programmes as a majority of the population are unlikely to be aware of certain disorders. These new developments combined with existing platforms and support systems such as 'Positive about Down Syndrome'⁷ will enable people to formulate a better link between genetics and the wider impact on society.

Overall, I believe that while the ability to carry out prenatal screening is a very important resource which gives people a great deal of freedom, it should not be accepted as a standard feature of reproductive healthcare that has to be undertaken under all circumstances. My piece is targeted towards a wide audience and its purpose is to generate a broad scope of discussion and debate instead of accepting things for the way they are. While historically women were discouraged from even thinking about disability during pregnancy, technology has expanded to allow much earlier and detailed results and the scientific benefits of this must not be underestimated. However, the ability to detect conditions significantly outweighs the ability to treat or cure them and this is the area which I believe requires considerable improvement. The law as stated in section 1(1)(d) of the Abortion act 1967 allows a pregnancy to be terminated if it is felt 'that there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped'⁸. This allows abortions to be justified under a number of circumstances, and is somewhat not reflective of the true reality of the conditions.

⁶ Felicity K. Boardman, Phillip J. Young, Oliver Warren, Frances E. Griffiths 'The role of experiential knowledge within attitudes towards genetic carrier screening: A comparison of people with and without experience of spinal muscular atrophy' (Wiley) (2017)

⁷ <https://positiveaboutdownsyndrome.co.uk/>

⁸ Abortion Act 1967, s 1(1)(d)

The two mothers that we were able to speak to during the information session on screening were very happy and positive about the future for their children despite their disabilities. While the nature of reproduction is shifting, it is highly important to gain insights from a variety of people and my drawing looks to highlight the importance of ensuring a balanced approach to avoid routinisation.

Bibliography

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