

GENERAL SYNOD

Valuing People with Down's Syndrome

(Note on terminology: Down syndrome, Down's syndrome and Trisomy-21 Anomaly are used by various groups and individuals to refer to the same condition. In this background paper, 'Down's syndrome' is used, in keeping with current NHS practice)

Introduction

1. People with Down's Syndrome are now living longer than ever before, they are receiving better healthcare and education and are experiencing greater social inclusion. Growing numbers of adults are in employment and enjoy leading independent or semi-independent lives and self-advocacy is on the rise. While more remains to be done, great strides have been made in recent decades to redress historic neglect.
2. The place within society of people with Down's syndrome and even their possible future existence are now under question, however, as a new form of prenatal screening begins to be rolled out this year within the NHS, with additional provision being offered by the private sector. Non-Invasive Prenatal Testing (NIPT) is not intrinsically problematic, but the manner in which it is introduced, understood and administered has the potential to lead to major reductions of Down's syndrome live births. In countries such as Iceland and Denmark, which have almost universal screening and close to 100% termination rates¹, there is a real possibility that people with Down's syndrome will effectively disappear from their populations. With a post-screening abortion rate of 90% within the UK², the introduction and potential widespread use of NIPT requires a timely debate on its possible consequences.
3. This paper provides information on Down's syndrome and current medical, educational and social practices as well as an introduction to NIPT. It also examines potential implications of NIPT and suggests ways in which it can be administered that enable women to make free and informed antenatal decisions. It begins by setting the theological context.

Being Human in Christ

'What are human beings that you are mindful of them, mortals that you care for them? Yet you have made them a little lower than God and crowned them with glory and honour' (Psalm 8: 4,5).

4. There is no hierarchy in God's love. God's love is for all of us, expressed supremely in Christ's death and resurrection offered for the whole of humankind. Christ's saving work is offered to everyone and his invitation to us is to respond to the best of our ability, whatever that may be. As outlined below, people with Down's syndrome have as much to give and share as anyone – their strengths and contributions may sometimes be different from those of others, but they are not less significant or less worthy of cherishing.
5. Despite the preoccupation in our culture with autonomy and self-reliance, the greater truth about being human is that we are all dependent upon others. In infancy, every

¹<https://www.healthline.com/health-news/the-debate-over-terminating-down-syndrome-pregnancies>

²<http://www.bbc.co.uk/news/magazine-37500189>

human being requires the nurture of others to survive, let alone flourish. In old age, most of us will rediscover our dependency on those around us. Even the adult years of supposed independence cannot be fruitful without dependency on others. In this, a cohesive human society reflects our dependency upon God, and the chimera of individual independence runs the risk of obscuring the nurturing and sustaining role of God in enabling us to be fully human.

6. Social attitudes to people with Down's syndrome have changed in recent decades, enabling people with Down's syndrome to achieve their potential more fully. In this respect, society at large has started to reflect the theological insight that we are all equally human before God.
7. None of this diminishes the challenges that attend a mother's discovery that she is expecting a child with Down's syndrome. It is natural to approach parenthood with high hopes for the child's future and the development of one's family. There are many reasons why these expectations may have to be revised but a diagnosis of Down's syndrome often necessitates a deep reappraisal. It is important that the church witnesses to the truth that our lives are in God's hands as are our own hopes and ambitions both for ourselves and for those we love. Where great challenges are placed before individuals, it is vital that the Christian community witnesses to our human solidarity as children of God, offering love and practical assistance; not asking the most vulnerable to bear the burdens that should properly be borne by all.
8. If we affirm the love of God for all, we must cherish people with Down's syndrome and their families so that they can flourish and be the gift to the community that God intends. Whilst celebrating technological advances that enable women to understand more about the development of their unborn children, an unintended consequence of this may be that, in the absence of full information about Down's syndrome and the support now available for both parents and children, the perceived challenges of living with Down's syndrome will result in more decisions to terminate. This, in spite of the growing social awareness that people with Down's syndrome are indeed fully human: in Christian terminology, made in God's image.

Understanding Down's Syndrome

9. Cause: Down's syndrome is caused by a chromosomal anomaly, most frequently occurring when all cells in a person's body have an extra chromosome 21 (95% of occurrences)³. Down's syndrome 'is not an illness but a term that describes the features resulting from this change'⁴. While Down's syndrome is a 'genetic' condition it is not usually heritable.
10. Prevalence: There are around 40,000 people with Down's syndrome in the UK (0.06% of the population; approximately one in every thousand live births). Around 750 children with Down's syndrome are born each year⁵. While the likelihood of having a child with Down's syndrome increases with maternal age, 80% of children with Down's syndrome are born to women under 35⁶.

³ The Down Syndrome Medical Interest group (DSMIG) UK and Ireland, <https://www.dsmig.org.uk/information-resources/by-topic/genetics/>

⁴ What is Down Syndrome? <https://www.medicalnewstoday.com/articles/145554.php>

⁵ Down's Syndrome Association, <https://www.downs-syndrome.org.uk/about/general/>

⁶ Ibid.

11. Health: Around half of children born with Down's syndrome have congenital heart defects and many encounter problems with their digestive systems. Sight and hearing impairments of varying intensity are also common as is increased risk of bacterial infections such as pneumonia. One in ten people with Down's syndrome experience thyroid problems⁷. 'Life expectancy of people with Down's syndrome has increased dramatically over the past century mainly due to improvements in access to cardiac surgery and better treatment of respiratory infections'⁸. Currently, in the UK, life expectancy is around 60 years of age⁹.
12. Development: Developmentally, the picture is varied. The Department of Education identifies both strengths and weaknesses for most children with Down's syndrome with characteristic strengths including social interaction, visual learning, gesture and mime, and reading ability. Characteristic weaknesses include learning to talk, learning to move, learning from listening and number skills¹⁰. Advances in supported learning have meant that very many children with Down's syndrome enjoy a mainstream education with some going on to third level education.
13. Mental Health: There is evidence that autism spectrum disorder occurs more frequently among people with Down's syndrome than in the general population¹¹. Dementia is also more prevalent and has an early onset with 10% of people aged 40-49 living with dementia with the incidence rising to 40% for those over 50 years of age¹².
14. Environment: Severity of physical or mental impairment are factors in people with Down's syndrome achieving optimal educational, employment and social attainments, but these are also dependent upon the levels of medical, educational and social support provided to them and their families. For example, employment levels for people with Down's syndrome stand at under 20%, a figure that is not representative of either their ability or desire to work¹³.
15. Resources: While, per capita, people living with Down's syndrome and their families require greater levels of medical and social support than many in the general population, their relatively small numbers mean that their 'resource allocation' is minor compared to resources associated with many other conditions.

Changes in Attitude

16. Since Down's syndrome was classified in 1866 major medical, educational and social advances have been made, leading to greatly improved outcomes for people with Down's syndrome.
17. Life expectancy in 1929 was only 9 years of age, rising to 12 by 1946, 25 by 1970, 49 by 1997 and 60 today¹⁴.

⁷ NHS Choices, <https://www.nhs.uk/conditions/downs-syndrome/complications/>

⁸ DSMIG, <https://www.dsmig.org.uk/information-resources/by-topic/general-medical-health/>

⁹ DSMIG, <https://www.dsmig.org.uk/information-resources/by-topic/adulthood-and-ageing/>

¹⁰ Early Support: Helping Every Child Succeed,

<http://webarchive.nationalarchives.gov.uk/20130321052927/https://www.education.gov.uk/publications/eOrderingDownload/ES13-2010.pdf>

¹¹ DSMIG, <https://www.dsmig.org.uk/information-resources/by-topic/autism-spectrum-disorder/>

¹² DSMIG, <https://www.dsmig.org.uk/information-resources/by-topic/dementia/>

¹³ <http://www.bbc.co.uk/news/blogs-ouch-32613957>

¹⁴ Global Down Syndrome Foundation, <https://www.globaldownsyndrome.org/about-down-syndrome/history-of-down-syndrome/research-and-medical-care-timeline/>

18. John Langdon Down's initial identification of the syndrome that came to bear his name was published in a work that he entitled 'Observations on an ethnic classification of idiots', using the term 'mongoloids' to describe people with the syndrome. In 1946, Dr Benjamin Spock in his book *Baby and Child Care* asserted that that 'babies born mongoloid should immediately be institutionalized' based on the premise that 'If [the infant] merely exists at a level that is hardly human, it is much better for the other children and the parents to have him cared for elsewhere'. In 1965 a delegation from Mongolia successfully petitioned the World Health Organisation to stop using the terms 'Mongol' or 'Mongoloid' to describe people with Trisomy 21 as this was viewed as being objectionable to the people of Mongolia¹⁵. This, rather than consideration of people with the condition, led to 'Down syndrome' or 'Down's syndrome' eventually becoming the standard descriptions of the condition by the 1970s¹⁶.
19. In 1979, research was published that described the impact of stimulation on infants and children with Down's syndrome and compared the IQs of children raised in institutions with those raised at home. Children with Down's syndrome raised in institutions had an average IQ of 20 to 30, while those raised at home with no specific attention to stimulation averaged about 40, and those raised at home with stimulation had an average IQ of 55¹⁷. Today, IQ is viewed as a questionable measurement of intelligence with models of multiple intelligence being preferred. Nonetheless, a wide range of IQ has been observed for people with Down's syndrome: while 50-60 is typical (akin to that of an eight/nine year old without Down's syndrome) some individuals have scored well over 100¹⁸. As further research is conducted into ways in which people with Down's syndrome learn and develop, higher attainments are most probable¹⁹.
20. During this century major improvements have been made to enable adults with Down's syndrome to live independent or semi-independent lives. With support, very many adults now make autonomous choices with regard to their lifestyles and growing numbers have become self-advocates, promoting better understanding of the condition as well as increased inclusion at all levels of society²⁰.
21. The Department of Education has summarised the current situation: 'It's impossible to predict outcomes for any individual child when they are very young, but it's important to understand that children and young people with Down syndrome in general are achieving much more than they did 25 years ago. People with Down syndrome are living longer and are learning to read, write and achieve more than was the case even 10 years ago. They often progress more slowly than other people, but if they are given opportunities to carry on learning, they can benefit from becoming lifelong learners, just like the rest of the population²¹.
22. In brief, while people with Down's syndrome (and their families) face particular challenges, increased understanding of the condition allied with improved medical,

¹⁵ What's in a Name? Leshin L (2011), <http://www.ds-health.com/name.htm>

¹⁶ Global Down Syndrome Foundation, <https://www.globaldownsyndrome.org/about-down-syndrome/history-of-down-syndrome/research-and-medical-care-timeline/>

¹⁷ Bennett FC, Sells CJ, Brand C. Influences on measured intelligence in Down's syndrome. *Am J Dis Child.* Jul;133(7):700-3. (1979)

¹⁸ http://www.henryspink.org/down's_syndrome.htm

¹⁹ Down Syndrome Education, <https://www.down-syndrome.org/en-gb/research/education-21/>

²⁰ Down's Syndrome Association, <https://www.downs-syndrome.org.uk/for-people-with-downs-syndrome/living-the-way-you-want/>

²¹ Early Support: Helping Every Child Succeed,

<http://webarchive.nationalarchives.gov.uk/20130321052927/https://www.education.gov.uk/publications/eOrderingDownload/ES13-2010.pdf>, p11.

educational and social support has transformed the outlook for very many individuals. Remaining challenges ought not to be minimised, but much progress has been made. Many people, however, remain unaware of much of this progress, relying on out-dated or inaccurate information²².

Partnership

23. Bodies such as the Down's Syndrome Medical Interest Group (UK and Ireland) provide clear and comprehensive information on healthcare for people with Down's syndrome and their families as well as guidance for health professionals²³. Established care pathways and developmental checks have been published by various local authorities and agencies such as the Royal College of Paediatrics and Child Health²⁴. The Department of Education has provided excellent tools for parents and teachers²⁵ as have advocacy groups such as Down's Syndrome Education²⁶. Models of social inclusion are actively promoted by bodies such as Mencap and the Down's Syndrome Association and self-advocacy is on the rise.
24. It is more difficult to assess the attitudes of individuals and groups to people with Down's syndrome and the degree of social inclusion that has been achieved. Employment opportunities are limited even though most businesses that do employ people with Down's syndrome indicate that this is a positive experience²⁷. A few people with Down's syndrome have been appointed to public positions or sit on decision-making bodies²⁸, but this is very much the exception to the rule. Some have become musicians, artists or run their own businesses, but this is also viewed as being exceptional²⁹. It is still unusual for people with Down's Syndrome to marry. While the well-publicised account of a child with Down's syndrome being refused Holy Communion³⁰ is a rare occurrence today, the degree of inclusion within the Church is open to question. Inclusion has come a long way from the nineteenth century, but it still has a long way to go.
25. Working in genuine partnership with parents of children with Down's syndrome and, in particular, with self-advocates is essential if inclusion is to become full reality. MPA is committed to following up this motion by working within the Church and with external partners to facilitate greater inclusion of people with Down's syndrome in both church and society.

²² For example, *Women's Knowledge, Attitudes, and Beliefs About Down Syndrome: A Qualitative Research Study*, Denise M. Levis, Shelly Harris, Nedra Whitehead, Rebecca Moultrie, Kara Duwe, and Sonja A. Rasmussen, *Am J Med Genet A*. 2012 Jun; 0(6): 1355–1362, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4706760/>

²³ DSMIG, <https://www.dsmig.org.uk/information-resources/guidance-for-essential-medical-surveillance/>

²⁴ RCPCH, Services for Children and Young People with Down Syndrome, <https://www.dsmig.org.uk/wp-content/uploads/2015/09/Draft-servcei-spec.pdf>

²⁵ Early Support: Helping Every Child Succeed, <http://webarchive.nationalarchives.gov.uk/20130321052927/https://www.education.gov.uk/publications/eOrderingDownload/ES13-2010.pdf>

²⁶ DSE, <https://www.down-syndrome.org/en-gb/resources/>

²⁷ The Value that Employees with Down Syndrome can Add to Organizations, <https://www.mckinsey.com/industries/social-sector/our-insights/the-value-that-employees-with-down-syndrome-can-add-to-organizations>

²⁸ <http://www.bbc.co.uk/news/av/magazine-28196677/the-parish-councillor-with-down-s-syndrome>

²⁹ <http://www.twominuteparenting.com/down-syndrome-careers/>

³⁰ <http://www.bbc.co.uk/news/uk-england-leeds-16626123>

Non-Invasive Prenatal Testing (NIPT)

26. At a point when inclusion has become firmly established as a key element in advancing the role of people with Down's syndrome, their place in society has been brought into sharp focus with the introduction and prospective wide-spread use of a recently developed prenatal screening technique.
27. Non-Invasive Prenatal Testing (NIPT) is a maternal blood test that can be conducted safely on pregnant women without risk to their developing fetuses. Fragments of foetal DNA circulate in mothers' plasma from around the 4th week of gestation and gain sufficient concentration for viable testing around week 10.
28. NIPT can screen for some chromosomal abnormalities with an overall success rate of around 98%. Testing can be conducted for Down's Syndrome, Edwards Syndrome, Patau Syndrome and Turner Syndrome. These tests are not yet wholly accurate, but if a positive test result occurs, women are advised to consider invasive testing (such as amniocentesis or chorionic villus sampling) in order to confirm or to eliminate a diagnosis.
29. Until recently, all pregnant women at 'high-risk' (approximately 10,000 each year with 65-70% uptake³¹) were offered invasive testing which can result in miscarriage (0.5-1% occurrence). NIPT will reduce the need for invasive testing for women at 'high risk' who do not test positive, hence preventing some miscarriages. It is estimated that around 1,500 women will opt for invasive testing after NIPT with about 1,000 positive diagnoses being made³².
30. Currently, the NHS plans to offer NIPT only to women identified as being at 'high-risk'. As 80% of children are born to women not in this category they will either remain unscreened through NIPT or choose to access screening through commercial providers, a number of which offer 'home-kits' via the internet.
31. NIPT offers many advantages: it is safe, it will result in decreased incidence of miscarriage and it provides women with important information. As, currently, 90% of women with positive diagnoses from invasive tests choose to terminate their pregnancies³³, it is important to examine the full potential implications of this new test.

Implications of NIPT

32. NIPT has the potential to offer women better access to information on which to make decisions with regard to their pregnancies.
33. The current law permits termination of pregnancies if 'the pregnancy has not exceeded its twenty-fourth week and the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman or any existing children of her family' or if 'there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as

³¹ Comparison of National Downs Screening Uptake, Results, and Outcomes to a District General Hospital
T Zehrer, I Stankeviciene, M Abdel-Aal, <https://fetalmedicine.org/abstracts/2014/abstracts/259.pdf>

³² <https://www.theguardian.com/society/2016/nov/04/new-prenatal-test-for-downs-syndrome-will-not-lead-to-more-terminations-nipt>

³³ Comparison of National Downs Screening Uptake, Results, and Outcomes to a District General Hospital
T Zehrer, I Stankeviciene, M Abdel-Aal, <https://fetalmedicine.org/abstracts/2014/abstracts/259.pdf>

to be seriously handicapped'³⁴. A diagnosis of foetal Down's syndrome is currently understood as providing grounds for termination of pregnancy for a number of reasons: mental health of woman, existing children, family members and serious 'handicap'.

34. The Church of England has a clear and established policy with regard to abortion: 'The Church of England combines strong opposition to abortion with a recognition that there can be - strictly limited - conditions under which it may be morally preferable to any available alternative'³⁵. 'In the rare occasions when abortion is carried out beyond 24 weeks, 'Serious foetal handicap' should be interpreted strictly as applying to those conditions where survival is possible only for a very short period'³⁶.
35. More recently the Church of England has stated, 'All abortions are tragedies, since they entail judging one individual's welfare against that of another (even if one is, as yet, unborn). We would like to see more support for women including access to information, advice and counselling, from a wide range of providers that would enable them to make a fully informed decision'³⁷.
36. While screening and potential termination of pregnancy form the context for NIPT, the underlying issue is the need for women to be given comprehensive, unbiased information so that they can make free and informed choices (regardless of whether one agrees or disagrees with the provisions of the 1967 Abortion Act).
37. This means that health professionals ought not to present a diagnosis of Down's syndrome as 'bad news' or that a discussion of termination ought to be initiated by them. It also means that women ought not to be placed under implicit or explicit pressure to undergo NIPT. Full information with regard to Down's syndrome ought to be provided and, if desired, discussed prior to testing and non-directive counselling offered in cases of positive diagnosis. It is particularly important that commercial practices are regulated. The need for professional training and provision of appropriate counselling is supported by many groups including the RCOG³⁸, The Down's Syndrome Association³⁹ and the Nuffield Council on Bioethics⁴⁰.
38. People with Down's syndrome are complete human beings, made in the image of God, deserving full inclusion in both church and society. It is imperative that every step is taken to ensure that they are welcomed, celebrated and treated with dignity and respect.

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³⁴ Abortion Act 1967, <https://www.legislation.gov.uk/ukpga/1967/87/section/1>

³⁵ (Briefing Paper prepared by the Mission and Public Affairs Council [MPA], endorsed by General Synod, February 2005)

³⁶ (1993 Resolution of General Synod)

³⁷ Press Statement issued by Mission and Public Affairs Division, 10th January 2013

³⁸ <https://www.rcog.org.uk/en/news/rcog-response-to-uknsc-recommendation-on-nipt-testing-for-high-risk-women/>

³⁹ <https://www.downs-syndrome.org.uk/news/tell-it-right-start-it-right-campaign-update-2016/>

⁴⁰ Nuffield Council on Bioethics, *Non-invasive prenatal testing: ethical issues* (2017), <http://nuffieldbioethics.org/wp-content/uploads/NIPT-ethical-issues-full-report.pdf>