

Introduction.

Down’s Syndrome is a condition which occurs when a baby is born with an extra copy of chromosome 21 in the cells of their body. According to The Down’s Syndrome Association (2021) two babies are born every day in the UK with Down’s Syndrome. Individuals who are born with Down’s Syndrome will have some level of learning disability, as well as physical and medical conditions which will affect them daily (NHS, 2019). The medical term used for having an extra copy of a chromosome is Trisomy, meaning Down’s Syndrome can be referred to as Trisomy 21. The National Down Syndrome Society (no date) states that there are three kinds of Down’s Syndrome: Trisomy 21, Mosaicism, and Translocation, which are determined and identified by how the cells are split during conception. The extra copy of chromosome 21 results in extra genetic material being present in a baby’s body which causes the typical features associated with Down’s Syndrome (Centers for Disease Control and Prevention, 2021). However, it is important to remember that each person with Down Syndrome is a unique individual and will possess these characteristics and features in varying degrees, and maybe not even at all (NDSS, no date).

Identification and Diagnosis.

The National Institute of Child Health and Human Development (2017) state that Health Care Providers can check for the presence of Down’s Syndrome during pregnancy through using screening tests such as blood tests and ultrasound scans within the first trimester of pregnancy. The cause of the extra chromosome is still unknown, with maternal age being the only factor that has been linked to an increased chance of a baby being born with Down’s Syndrome (NDSS, no date). However, pre-natal screening tests cannot say for definite if Down’s Syndrome is present in the foetus. A follow up diagnostic test is offered to high chance mothers, and it is this test that will determine with certainty that Down’s Syndrome is present (NCIHD, 2017). There are two kinds of diagnostic tests that are offered to mothers which are an amniocentesis test and Chorionic Villus Sampling. However, neither of these tests come without risk as there is a 1 in 100 chance of miscarriage occurring as a result (NHS, 2019). In 2018, an advanced screening test was offered to high chance expectant mothers in Wales known as a Non-Invasive Pre-natal Test (Public Health Wales, 2018). In order to confirm the presence of Down’s Syndrome at birth, a chromosomal analysis, called a karyotype is carried out by health care professionals (NDSS, no date). According to Jones (2020) 90% of women whose unborn babies are diagnosed with Down’s Syndrome choose to terminate the pregnancy, which can be carried out at any time during the pregnancy. In comparison, the legal abortion limit for a ‘healthy’ foetus’ is 24 weeks.

Barriers and Challenges.

Babies who are born with Down’s Syndrome are at an increased risk of developing medical implications, which can include vision and hearing impairments, and heart defects (Jarvis, 2021). The Down Syndrome Medical Interest Group (no date) state that there are conditions which could affect children’s eyesight, including congenital cataract and glaucoma, alongside over 50% of children with Down’s Syndrome needing glasses by the time they reach primary school. Hearing impairments play a significant role in the challenges that are faced daily with 80% of children with Down’s Syndrome experiencing some form of hearing loss (The National Deaf Children’s Society, 2022). Down Syndrome Education (2022) highlight that congenital heart defects occur within around 47% of individuals born with Down’s Syndrome with 10-15 % of babies having a severe heart defect. People with Down’s Syndrome will also have social barriers to contend with, such as pre-conceived perceptions that have been around for many years (ITV News, 2019). It wasn’t until the 1980’s that children with Down’s Syndrome were allowed to attend mainstream schools with their peers. Children with Down’s Syndrome were supported further in 2006 with the introduction of the United Nations Convention on the Rights of Persons with Disabilities. The NDSS (no date) states the importance of using appropriate language when referring to an individual with Down’s Syndrome, for example, people should say a child with Down’s Syndrome and not a Down’s Syndrome child.

Strategies.

Established in 1970, The Down’s Syndrome Association is a national organisation that is committed to improving the quality of life for people with Down’s Syndrome. The NDSS (2022) state that the first few years of a child’s life are critical to their development, therefore, early intervention is crucial. The three kinds of early interventions are: Physical Therapy, Speech and Language Therapy and Occupational Therapy. Victoria State Government (2021) state the importance of remembering that all families are different and will need differing levels of support. The NDSS (2022) offers that early intervention can enhance and accelerate a child’s development through building on their strengths and through strengthening skills that need developing further. Victoria State Government (2021) understand and value the importance of a supportive family network and recognise that such networks have been the driving force behind many of the progressive changes that have impacted the lives of children with Down Syndrome. In 2018, the Welsh Government passed a new legislation, known as the Additional Learning Needs Education Tribunal (Wales) Act 2018, which replaced all existing legislation and guidance about special educational needs (Snap Cymru, no date). Furthermore, in 2021, history was made with the first legislation passed by Parliament to support and empower people with Down’s Syndrome (Sky News, 2021). This legislation became the Down Syndrome Act 2022 and is a legal guarantee to ensure that health, education, and social care needs are met for individuals with Down’s Syndrome, with the hope of improving people’s knowledge and understanding and to hopefully end the stigma that is associated with Down’s Syndrome.

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