

### Introduction

According to NHS (no date); Down's Syndrome Association (2021) they define Down's Syndrome as someone who is born with an extra chromosome, which is purely by chance of a change in the sperm or egg before they are born.

Down Syndrome UK (2024) say that babies can be born to parents of all ages, race, and backgrounds and even though people with Down Syndrome can have common physical characteristics, every person is individual with their own strengths and weaknesses, and they form a personality and characteristics from the influences of the people that are around them.

### Diagnosis

NHS (no date) ; Down's Syndrome Association (2021) say that you are offered screening tests for Down's Syndrome between 10 and 14 weeks into your pregnancy. It involves an ultrasound and blood test, which usually coincides with the 12-week scan. It is recommended more so if you are older as there is more chance of an abnormality. If the results from this shows a positive sign for an anomaly, Jarvis (2021) says additional tests called amniocentesis or chronic villus sampling can be carried out but do carry risks such as miscarriages. It then becomes a decision for the parents to decide to go through with the pregnancy or to have a termination.

Down's Syndrome Association (2021) view on prenatal testing is that the absence of individuals with Down's Syndrome from the world would not be desired as they contribute greatly to their families, communities, and society at large in a variety of ways.

Down's Syndrome Association (2021) acknowledges that prenatal testing is part of the routine of antenatal care, and it is the choice of the parent whether they have the test or not, but along with Down Syndrome UK (2024) they want to make sure that parents are given all the information of what to expect when having a baby with Down's Syndrome.

# Down's Syndrome

Natalie Herdman 2213358

### Barriers

A perspective of the world has been formed by people with disabilities which is called social model of disability. The model demonstrates that barriers in society such as accessibility, people's attitudes to difference and their assumptions of what disabled people can do are the barrier rather than the impairment and difference itself (Scope, no date; Haegele and Hodge 2016). However, Owens (2014) says the existence of multiple versions of the social model of disability seems to contribute to the misunderstandings around it. Despite the fact these many forms emerged almost simultaneously they occupy many historical and political contexts which adds to the conflicts.

Another model is called the medical model of disability, this is where the person's needs are ignored in favour of focusing on what is 'wrong' with them, which Scope (no date); Haegele and Hodge (2016); Smeets and Roeleveld (2016) says lowers expectations and causes people to lose the sense of self, autonomy, and control of their lives.

Research by Macintyre (2014) says that the signs of Down's Syndrome are apparent as the baby is likely to be small and lacking in muscle tone, babies' eyes are almond shaped and very often the tongue protrudes, which some parents can find difficult to deal with. Furthermore, research by Broomhead (2019) examined the influence the child's disability has on stigmatisation for the parents, the findings showed that the reactions of others were determined by three key factors, the visibility of the disability, the behaviour of the child and whether it was deemed acceptable and the ability to control the disability and whilst some parents of what was seen as socially unacceptable behaviour received negative responses other parents received pity.

There are many other barriers that children with Down's Syndrome face such as issues with speech, language and communication, vision and hearing, heart conditions and physical difficulties. This means that activities may need to be adapted for children so that they are included in provision however research by Pit-ten-Cate et al. (2018); Pit-ten Cate et al. (2019) say that although inclusive practice should start with the teacher, they need to have the knowledge and understanding of inclusivity and also have the values and beliefs for inclusion in practice however the research shows that teachers feel underprepared and less willing to include children with additional learning needs.

### Strategy

People with Down's Syndrome will have some form of learning disability according to NHS (no date); Down's Syndrome Association (2021), which Sheffield Children's NHS (no date) ; Macintyre (2014) agree with and say while each child with Down's syndrome is unique and has their own personality, skills, and weaknesses, there are some traits that they all share, such the ability to hear, understand, and use language, as well as the ability to speak, eat, and drink.

According to Dr Burgoyne (2020); Down's Syndrome Association (2021) language is essential for all aspects of learning and social development, so providing children with a Speech and Language therapist is vitally important. Each child learns in a unique way, so the programme plan needs to be individualised to the child's strengths and weaknesses. Most children with Down's Syndrome will need support with attention, working memory, understanding of language, expressive language, speech clarity, dysfluency, eating and drinking and vision and hearing.

From birth a speech and language therapist can help support children communicate with people, firstly they will focus on sounds, gestures, and expressions, then will move onto using Makaton signs in their daily routine so that children can help to connect the word and sign to an item or action (Down Syndrome UK, 2021).

In school settings the Speech and Language therapist will attend at least once a month, providing support for the support worker and parents, they will also advise on additional ways of communicating such as Makaton and See and Learn as children with Down's Syndrome learn best visually (Down Syndrome Association, 2021).

### Conclusion

To summarise Down's Syndrome is still seen by some people including medical practitioners as something that is a negative, however agencies such as Down's Syndrome Association (2021) and Down Syndrome UK (2024) are providing information for parents to ensure that they are getting all the information they need to make an informed decision. However, these charities and the education system are facing difficulties due to budget cuts, which is not enabling practitioners to access much needed training and support that they require to ensure inclusivity for all.

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The additional learning need I have chosen to talk about today is Down Syndrome. I have worked in childcare for over 25 years and have only ever worked with one child with Down's Syndrome and I wondered why that was? After speaking with colleagues from the Flying Start inclusion team, children have accessed Flying Start, just not in the areas I work, which is good to hear, but I am now interested to know what type of provision is available and if extra support is needed for them.

So firstly, what is Down Syndrome.

According to NHS (no date); Down's Syndrome Association (2021) they define Down's Syndrome as someone who is born with an extra chromosome, which is purely by chance of a change in the sperm or egg before they are born.

Down Syndrome UK (2024) say that babies can be born to parents of all ages, race, and backgrounds and even though people with Down Syndrome can have common physical characteristics, every person is individual with their own strengths and weaknesses, and they form a personality from the influences of the people that are around them.

Down Syndrome UK (2024); Kusre, Shankarishan and Nirmolia (2016) say that there are 3 types of Down Syndrome, which are identified at birth. Firstly, there is trisomy 21, which is the most common, 95% of the Down Syndrome population have this type. Secondly, there is translocation, only 2-3% of babies are born with this type, which has an extra part or whole extra copy of chromosome 21 attached to a different chromosome. The final type of Down Syndrome is mosaicism, again 2-3% of the population have this type, this is where they have chromosome 21 in only 1% of a body cell and the rest of the cells have none.

How people get a diagnosed?

NHS (no date); Down's Syndrome Association (2021) say that you are offered screening tests for Down's Syndrome between 10 and 14 weeks into your pregnancy. It involves an ultrasound and blood test, which usually coincides with the 12-week scan. It is recommended more so if you are older as there is more chance of an abnormality. If the results from this shows a positive sign for an anomaly, Jarvis (2021) says additional tests called amniocentesis or chronic villus sampling can be carried out but do carry risks such as miscarriages. It then becomes a decision for the parents to decide to go through with the pregnancy or to have a termination.

Down's Syndrome Association (2021) view on prenatal testing is that the absence of individuals with Down's Syndrome from the world would not be desired as they contribute greatly to their families, communities, and society at large in a variety of ways. Down's Syndrome Association (2021) acknowledges that prenatal testing is part of the routine of antenatal care, and it is the choice of the parent whether they have the test or not, but along with Down Syndrome UK (2024) they want to make sure that parents are given all the information of what to expect when having a baby with Down's Syndrome.

Down Syndrome UK (2024) have a Positive about Down Syndrome group which gives support and information to every expectant parent of a baby with Down Syndrome. Additionally, Down's Syndrome Association (2021) gives information on the impact of families, life prospects of people who have Down's Syndrome and offer counselling services to those who need it.

Notably a report from Jones (2020) explained that a parent who was older was given negative responses to the fact that they refused an additional test and when the midwife found out that the child did have Down's Syndrome the only offer of support was for an abortion. Additionally, Jones (2020) reported of a parent who was younger and was still offered an abortion as her child had Down's Syndrome and was told that until the child is travelling down the birth canal a termination is an option.

This is what campaigners in the BBC News (2020) are fighting against. They believe that the 24-week standard abortion limit should be introduced for all non-fatal disabilities found during pregnancy. One campaigner who herself has Down's Syndrome feels that allowing termination up to the point of birth makes her feel unloved and unwanted.

A survey conducted by Kellogg *et al.* (2014) with parents with a Down's Syndrome baby asked for their views on prenatal testing. Many of the responses were that they would recommend the testing, however the vast majority believe that this would increase the level of terminations if the tone and content of the information given to the families were negative. Kellogg *et al.* (2014); Gupta and Kabra (2014) believe that professionals should strive to provide a balanced view showing the pros and cons of having a baby with Down's Syndrome and that all information provided should be up to date and resources given to offer support for all choice.

However, in a study by Bakst *et al.* (2019) there are conflicting views with regards to prenatal testing in certain cultural backgrounds, such as Jewish and Arab communities. Bakst *et al.* (2019) believes that pregnant women in these communities need to have culturally competent counselling explaining the process and discussing individual preferences would help to build the understanding of pre-natal testing.

Moreover, according to Finkelstein *et al.* (2023) health professionals play a vital role in parental experiences of being told their baby has Down Syndrome, however most of the Jewish mothers surveyed by Finkelstein *et al.* (2023) felt that they were unsupported during this process, and few were congratulated.

### What barriers could people face?

A perspective of the world has been formed by people with disabilities which is called social model of disability. The model demonstrates that barriers in society such as accessibility, people's attitudes to difference and their assumptions of what disabled people can do are the barrier rather than the impairment and difference itself (Scope, no date; Haegele and Hodge 2016). However, Owens (2014) says the existence of multiple versions of the social model of disability seems to contribute to the misunderstandings around it. Despite the fact these many forms emerged almost simultaneously they occupy many historical and political contexts which adds to the conflicts.

Another model is called the medical model of disability, this is where the person's needs are ignored in favour of focusing on what is 'wrong' with them, which Scope (no date); Haegele and Hodge (2016); Smeets and Roeleveld (2016) says lowers expectations and causes people to lose the sense of self, autonomy, and control of their lives. Haegele and Hodge (2016) research showed that this was the case for a student they observed and how the teacher's opinions on the disability could affect the outcome for the students in their care if they all viewed the child in a medical model rather than the social model of disability.

Additionally, research by Banbury (2019) says that law has used the medical model of disability, which is suggested has added to the segregation and discrimination to disabled people. Banbury (2019) believes that the Equality Act 2010 should follow the social model of disability in so allowing a positive force to reduce discrimination and transform attitudes.

Thomas (2020) interviewed parents of children with Down Syndrome on how they felt about the media portrayal of Down Syndrome and whilst parents did praise the portrayals they did have concerns about the tokenism, stereotyping and the focus of 'exceptional' people which could obscure the reality of what parents with disabled children deal with every day.

Research conducted by Alhaddad *et al.* (2018) studied people's perceptions, attitudes, and knowledge of Down Syndrome and how this could influence the individual and concluded that people are missing key factors of the knowledge and understanding which could lead to unfavourable attitudes towards people with Down Syndrome.

Additionally, research by Macintyre (2014) says that the signs of Down's Syndrome are apparent as the baby is likely to be small and lacking in muscle tone, babies' eyes are almond shaped and very often the tongue protrudes, which some parents can find difficult to deal with. Furthermore, research by Broomhead (2019) examined the influence the child's disability has on stigmatisation for the parents, the findings showed that the reactions of others were determined by three key factors, the visibility of the disability, the behaviour of the child and whether it was deemed acceptable and the ability to control the disability and whilst some parents of what was seen as socially unacceptable behaviour received negative responses other parents received pity.

Moreover, research by Holland and Pell (2018); Desimpelaere *et al.* (2023) show the unique challenges in raising a child with Down Syndrome can bring, such as higher parental stress and low wellbeing. Parents sense of competence, personal autonomy, and family dynamics can also be affected.

However, it is possible for parents to experience both happiness and stress, negative emotions, and grief when raising a child with an additional need. Research by Farkas *et al.* (2018) investigated the positive and negative effects of having a child with Down Syndrome and found that parents encounter developmental, medical, educational, and social challenges that most parents of typically developing children do not experience. However, the experience that these parents have need to be valued as their perspectives and contributions can enable the social acceptance and inclusion for everyone.

There are many other barriers that children with Down's Syndrome face such as issues with speech, language and communication, vision and hearing, heart conditions and physical difficulties. This means that activities may need to be adapted for children so that they are included in provision however research by Pit-ten-Cate *et al.* (2018); Pit-ten Cate *et al.* (2019) say that although inclusive practice should start with the teacher, they need to have the knowledge and understanding of inclusivity and also have the values and beliefs for inclusion in practice however the research shows that teachers feel underprepared and less willing to include children with additional learning needs.

Furthermore, a study by Dougals *et al.* (2016) examined how children are assessed within schools and found that although some areas included all, the inclusive framework assessment which ensures the breadth of the curriculum was not, leading to a failure in assessing and celebrating progress of a wide range of students.

Moreover, research by National Association for Head Teachers (2021) say that 97% of schools in England believe that they have insufficient funding for special educational needs and disability pupils and 73% report that they are funding the health and social care support within the school as services have been cut.

### What strategy could help?

People with Down's Syndrome will have some form of learning disability according to NHS (no date); Down's Syndrome Association (2021), which Sheffield Children's NHS (no date) ; Macintyre (2014) agree with and say while each child with Down's syndrome is unique and has their own personality, skills, and weaknesses, there are some traits that they all share, such the ability to hear, understand, and use language, as well as the ability to speak, eat, and drink.

According to Dr Burgoyne (2020); Down's Syndrome Association (2021) language is essential for all aspects of learning and social development, so providing children with a Speech and Language therapist is vitally important. Each child learns in a unique way, so the programme plan needs to be individualised to the child's strengths and weaknesses. Most children with Down's Syndrome will need support with attention, working memory, understanding of language, expressive language, speech clarity, dysfluency, eating and drinking and vision and hearing.

From birth a speech and language therapist can help support children communicate with people, firstly they will focus on sounds, gestures, and expressions, then will move onto using Makaton signs in their daily routine so that children can help to connect the word and sign to an item or action (Down Syndrome UK, 2021).

Moving forward additional signs are added and advise on how to form speech sounds and games on how to promote attention and listening skills. The speech and language therapist will work with parents at home and provide support to settings too (Down Syndrome UK, 2021).

Additionally, children who attend a Flying Start setting will have access to an inclusion team, who help to support the staff in the child's transition into the nursery, offer training and guidance so that the setting remains fully inclusive and meet the needs of all the children in their care (Flying Start, no date).

In school settings the Speech and Language therapist will attend at least once a month, providing support for the support worker and parents, they will also advise on additional ways of communicating such as Makaton and See and Learn as children with Down's Syndrome learn best visually (Down Syndrome Association, 2021).

Makaton (no date) say that using the signs, symbols, and speech help language development in people with Down's Syndrome as they can communicate their needs effectively and according to Macintyre (2014); See and Learn helps children to learn early speech, language, reading and numeracy skills from birth to early school years (Down Syndrome Education, 2024).

However, research by Kendall (2017) in a mainstream school with children who have Down's Syndrome shows that there were barriers to ensure the successful inclusion of children, such as lack of teachers throughout the school learning Makaton and teacher's feelings of children attending mainstream school due to their lack of confidence and training with children having Down's Syndrome.

Furthermore, research by Ellis and Tod (2014) suggests that 70% of the teachers included in their study reported that they felt inadequately prepared to teach children with special educational needs and 60% of those teachers wanted to know more to help support children.

However, the Royal College of Speech and Language Therapists (2024) have called upon Jeremy Hunt MP to use the forthcoming budget to ensure that funding is provided for Speech and Language therapy to meet the increasing demand for the service, including the early intervention of early language skills.

Moreover, according to a professional body survey, the number of openings for speech and language therapy in the UK has reached 23%. Nearly all children's services reported that recruitment is more difficult than it has been in the previous three years. The Covid-19 pandemic increased the demand on the service, lengthening the wait periods for evaluation and assistance, and increasing the number of referrals for the assessment of young children who's social and language development was hindered by pandemic restrictions (Independent, 2023).

### Conclusion

To summarise Down's Syndrome is still seen by some people including medical practitioners as something that is a negative, however agencies such as Down's Syndrome Association (2021) and Down Syndrome UK (2024) are providing information for parents to ensure that they are getting all the information they need to make an informed decision. However, these charities and the education system are facing difficulties due to budget cuts, which is not enabling practitioners to access much needed training and support that they require to ensure inclusivity for all.

Does anyone have any questions?

QUESTION- What is another barrier for Down's Syndrome children?

- As previously discussed
- Children with Down Syndrome health can be affected.
- They are more prone to infections.
- lead to time off school which could put them further behind with their learning.
- And stop relationships being formed with friends.
- NHS (no date)

QUESTION – What other strategies are there?

- Many other strategies for children with Down Syndrome to access
- Occupational therapy – they will
- Assess different skills
- determine needs
- Fine and gross motor
- Cognitive
- Sensory regulation
- Woods (2022)
- AND

## Physiotherapy

- Develop gross motor skills.
- Rolling, crawling sitting standing
- Later, so that they are included in school activities.
- Running, skipping, hopping, and climbing
- National Down Syndrome Society (2023).