

Embracing diversity: Down syndrome

What is Down syndrome?

Down syndrome is an example of a chromosomal additional learning need. National Down Syndrome Society (2024a), states that Down syndrome occurs when a person has an extra copy of chromosome 21. Down Syndrome Association (2021) says that learning disabilities usually occur with Down syndrome. While people with Down syndrome may have physical characteristics such as a small structure and an upward slant in their eyes, it is sufficient to recognise that each person with Down Syndrome is unique. These qualities vary in intensity from person to person, highlighting the diversity of the Down syndrome population (NDSS, 2024).

Diagnosis pre birth

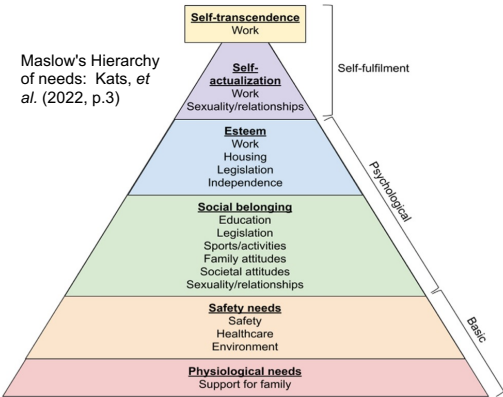
NHS (2023) states that down syndrome can be diagnosed between weeks 10-14 of pregnancy through a blood test. According to National Down Syndrome Society (2024) the blood test relies on the detection of cell-free DNA and can detect up to 98.6% of fetuses with Down Syndrome. However, NDSS (2024) states that many expecting parents choose not to have the test as it is the parents' decision if they want it. This results in most cases of Down syndrome being diagnosed after the baby is born. Parents may opt out of the test to discover if their child has Down syndrome as Peditr (2023) and Mencap (no date, p.1) says that expecting parents might experience increased anxiety. This is due to the availability of information on the internet can often result in the publishing of incorrect or false opinions, unintentionally influencing preconceptions. Also, Mencap (no date, p.1) says that parents might find it a challenge to come to terms with the fact that their child's future might be different than they might have imagined. However, an advantage of the Down syndrome diagnosis is the fact that it is during pregnancy. This allows parents to prepare emotionally and gather information about the condition enabling them to plan for appropriate support for their child from the moment of birth. According to NDSS (2024b) due to the early diagnosis of Down syndrome parents can access early intervention to support their child. Through early intervention carers and professions can provide targeted support, boosting the child potential. This includes speech therapy, occupational therapy and physical therapy says Jones (2016, p.174).

Communication barriers

Children with Down Syndrome may encounter challenges in communication, as highlighted by the Down Syndrome Association (2005, p.6). This can cause difficulties in expressing themselves, understanding others, and engaging in social interactions. However, a promising avenue for effective communication lies in the use of Makaton, as indicated by Makaton (2023). Makaton, a system of communication that combines speech, signs, and symbols, has been shown to facilitate effective communication for individuals with Down syndrome (Makaton, 2023). The Down Syndrome Association (2021b, p.1) suggests that visual support tools like Makaton signs can significantly aid in the speech and language development of children with Down syndrome. Despite these benefits, Foreman and Crews (1998, p.17) suggest that parents may be reluctant in utilising Makaton with their children. This reluctance could stem from various factors, such as the fear that relying on sign language may impede the development of verbal language, concerns regarding the stigma associated with using Makaton in a predominantly speaking society, and the perceived complexity of learning the signs for both the child and the family (Foreman and Crews, 1998, p.17). On the contrary, according to PACEY (2019) the ability to communicate with Makaton not only builds confidence and independence in children, but also supports their communication and language abilities. However, in a setting, children with Down syndrome may struggle to communicate to practitioners and peers due to them not knowing Makaton signs. Which could result in children who understand more than they can communicate feeling frustrated (Foreman and Crews, 1998, p.17). This could be supported through professional development for practitioners. Although, Eroglu and Kaya (2021, p.1904) highlight that the timing of training sessions sometimes causes inconvenient for teachers, as they class with work schedules making it a challenge for them to participate. The lack of training and sufficient information about various ALN's, could make teachers feel unprepared to effectively support these children in the classroom suggests McFadden, Tangen, Spooner-Lane and Mergler (2017, p.4).

Summary

In conclusion early diagnosis of Down syndrome, whether pre-birth or just after, grants parents' access to crucial early intervention services that support the child and their family. Although, children with Down syndrome often face communication challenges, posing barriers to learning. These barriers stem from inadequate training for teachers on addressing additional learning needs and utilising tools like Makaton. Furthermore, while 1:1 support in schools is essential for inclusive classroom environments, it may potentially impede the child's independence. Which means that there is a need for a balanced approach that fosters both support and independence for children with Down syndrome.



1:1 support

Teachers express concerns about their ability to effectively manage the class while attending to a student with an additional learning needs states McFadden, *et al.* (2017, p.3). To overcome this challenge, children with Down syndrome could benefit from a 1:1 support strategy. This approach not only assists individual students but also fosters inclusive environments that acknowledge and accommodate the diverse needs of children, facilitating their full participation in the learning process (Welsh Government, 2022, p.44). This principle aligns with the rights of people with disabilities, Article 5 which states that disabled people's full participation and inclusion in society must be supported (Equality and human rights commission, no date, p.15). Research indicates that children with Down syndrome can thrive academically and socially within mainstream education when provided with appropriate support, such as the 1:1 support from a practitioner. Boundy, *et al.* (2023, p.3) highlight that 95% of pupils with Down syndrome in mainstream schools receive 1:1 support. The curriculum for funded non-maintained settings (2022, p.24) is designed to recognise and celebrate the individuality of each child, which underscores the importance of tailored support, particularly in the form of 1:1 assistance for children with Down syndrome. By acknowledging and addressing their specific needs, such as assistance with tasks like toilet training, this support fosters a sense of security and enables them to progress towards fulfilling higher levels of Maslow's hierarchy of needs (Kats *et al.*, 2022, p.3). In this way, the curriculum (Welsh Government, 2022, p.44) ensures that children with Down syndrome are fully included and supported in the learning experience, allowing them to thrive and contribute meaningfully. However, while support is essential for enabling students with Down syndrome to access the learning environment, it is equally crucial to provide them with opportunities to develop their independence. As, Hargreaves, *et al.* (2021, p.11) argues that excessive adult supervision could hinder the development of friendships and independence. Additionally, while establishing emotional attachments between the practitioner and child allows for more personalised learning as they will know the child's likes and dislikes, it could lead to overdependence on the 1:1 support. Giangreco (2009, p.3) states that this becomes problematic in situations where there are no plans in place to fade the support.

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Presentation script

Introduction

Hi everybody, my name is Ashley Murphy and my chosen ALN for this webinar is Down Syndrome. Down syndrome is a prime example of a chromosomal additional learning need. According to the National Down Syndrome Society (2023a), it happens when someone has an extra copy of chromosome 21. According to the Down Syndrome Association (2021) people with Down syndrome commonly encounter challenges with learning.

While physical traits like as a small structure and an upward slant in the eyes are frequently associated with Down syndrome, it is important to recognise that each person with Down syndrome is unique. These features differ in person from person to person highlighting the vast diversity of the Down syndrome population (NDSS, 2024).

Diagnosis

Now, let's delve into how Down syndrome is diagnosed. According to the NHS (2023), a blood test can often diagnose Down syndrome between weeks 10 and 14 of pregnancy. National Down syndrome society (2024) says that this test uses cell-free DNA to identify fetuses with Down syndrome and has a successful accuracy rate, detecting up to 98.6% of them. Despite its reliability, NDSS (2024) states that many expectant parents choose not to take this test, as the decision is ultimately theirs. As a result, most Down syndrome cases are discovered after birth. Doctors often detect Down syndrome based on physical indications such as reduced muscular tone, a flattened facial profile, and an upward slant in the eyes. While not all babies with Down syndrome exhibit these qualities, the National Down Syndrome Society (2014) points out that many of these traits can also be found in people who do not have the disability. This emphasises each individual's uniqueness, as well as the diversity of the Down syndrome population.

Several reasons can impact the decision not to undergo parental testing. According to Paediatric (2023) and Mencap (no date, p.1), expectant parents may suffer increased anxiety if they take the test. This fear may originate from the vast amount of information available on the internet, which can occasionally contain disinformation and biased perspectives, forming preconceived opinions. Furthermore, while prenatal testing for Down syndrome has become more accurate, there is still a risk of a false positive results. These false results can cause unnecessary anxiety and concern for expectant parents until additional confirmation testing is performed. In addition, Mencap (no date, p.1) emphasises the difficulty parents confront in accepting potential variations in their child's future from their initial expectations. However, one advantage of detecting Down syndrome during pregnancy is that it allows for emotional preparation and information gathering regarding the condition. This proactive strategy can help parents better recognise and prepare for their child's particular needs.

Early diagnosis, as emphasised by NDSS (2024b), empowers parents to plan for their child's support from birth. This is crucial because the early years of a child's life are critical to their development says NDSS (2024b). Given that children with Down syndrome may reach developmental milestones at varying rates, early intervention becomes an important part of their development. Through early intervention, parents and professionals can provide targeted support to optimise the child's potential. Jones (2016, p.174) further highlights that this support may encompass various therapies like speech therapy, occupational therapy, and physical therapy.

Barriers

I will now move onto barriers. Children with Down Syndrome may encounter challenges in communication, as highlighted by the Down Syndrome Association (2005, p.6). This can cause difficulties in expressing themselves, understanding others, and engaging in social interactions. However, a promising avenue for effective communication lies in the use of Makaton, as indicated by Makaton (2023). Makaton, a system of communication that combines speech, signs, and symbols, has been shown to facilitate effective communication for individuals with Down Syndrome (Makaton, 2023).

The Down Syndrome Association (2021b, p.1) suggests that visual support tools like Makaton signs can significantly aid in the speech and language development of children with Down Syndrome. Despite these benefits, Foreman, and Crews (1998, p.17) suggest that parents may exhibit reluctance in utilizing Makaton with their children. This reluctance could stem from various factors, such as the fear that relying on sign language may impede the development of verbal language, concerns regarding the stigma associated with using Makaton in a predominantly speaking society, and the perceived complexity of learning the signs for both the child and the family (Foreman and Crews, 1998, p.17). On the contrary, PACEY (2019) underscores the transformative impact of Makaton, emphasizing that its utilization not only instils confidence and independence in children but also supports the enhancement of their communication and language skills.

However, within educational settings, children with Down Syndrome may encounter communication barriers with practitioners and peers who are unfamiliar with Makaton signs. This lack of mutual understanding may lead to frustration, especially for children who comprehend more than they can effectively communicate (Foreman and Crews, 1998, p.17). Addressing this challenge necessitates providing professional development opportunities for practitioners. Nonetheless, as noted by Eroglu and Kaya (2021, p.1904), the timing of training sessions often poses a significant obstacle for teachers, as they often coincide with their work schedules, finding that participation in such sessions can be challenging. The lack of training and sufficient information about various ALN's, could make teachers feel unprepared to effectively support these children in the classroom says McFadden, Tangen, Spooner-Lane and Mergler (2017, p.4). McFadden, Tangen, Spooner-Lane and Mergler (2017, p.3) also highlights that while practitioners support the idea of including children with disabilities in their classroom, they often lack the necessary skills to effectively educate these students.

Support

I will now be evaluating about 1:1 support. So, to begin, teachers express concerns about their ability to effectively manage the entire class while attending to a student with an additional learning need suggests. McFadden, *et al.* (2017, p.3). To overcome this challenge, children with Down syndrome could benefit from a 1:1 support strategy. This approach not only assists individual students but also fosters inclusive environments that acknowledge and accommodate the diverse needs of children and their families, facilitating their full participation in the learning process (Welsh Government, 2022, p.44). This principle aligns with the rights of people with disabilities, Article 5 which states that disabled people's full participation and inclusion in society must be supported says Equality and human rights commission (no date, p.15). Research indicates that children with Down syndrome can thrive academically and socially within mainstream education when provided with appropriate support, such as the 1:1 support strategy. Boundy, *et al.* (2023, p.3) highlight that 95% of pupils with Down syndrome in mainstream schools receive 1:1 support. The curriculum for funded non-maintained settings (2022, p.24) is designed to recognise and celebrate the individuality of each child, which underscores the importance of tailored support, particularly in the form of 1:1 assistance.

By acknowledging and addressing their specific needs, such as assistance with tasks like toilet training, this support fosters a sense of security and enables them to progress towards fulfilling higher levels of Maslow's hierarchy of needs (Kats *et al.*, 2022, p.3). In this way, the curriculum (Welsh Government, 2022, p.44) ensures that children with Down syndrome are fully included and supported in the learning experience, allowing them to thrive and contribute meaningfully. For example, having the 1:1 support the children can be encouraged to use Makaton to communicate to the other children. An example being if a child asks if they need a glue stick, the practitioner could encourage the use of Makaton to sign thank you, allowing the child to interact with peers.

However, while support is essential for enabling students with Down syndrome to access the learning environment, it is equally crucial to provide them with opportunities for independent development. Hargreaves, *et al.* (2021, p.11) argues that excessive adult supervision could hinder the development of friendships and independence.

Additionally, while establishing emotional attachments between the practitioner and child allows for more personalised learning as they will know the child's likes and dislikes, it could lead to overdependence on the 1:1 support. Giangreco (2009, p.3) states that this becomes problematic in situations where there are no plans in place to fade the support. Implementing scaffolding techniques to gradually give the child more independence is an example of one way to fade the one-to-one support as the child progresses in their development.

Conclusion

In conclusion early diagnosis of Down syndrome, whether pre-birth or just after, grants parents' access to crucial early intervention services that support the child and their family. Although, children with Down syndrome often face communication challenges, posing barriers to learning. These barriers stem from inadequate training for teachers on addressing additional learning needs and utilising tools like Makaton. Furthermore, while 1:1 support in schools is essential for inclusive classroom environments, it may potentially impede the child's independence. Which means that there is a need for a balanced approach that fosters both support and independence for children with Down syndrome. Thank you for listening to my presentation.

Questions

Holly: Yes, I have a question, can you elaborate on how; 1 to 1 support can prevent the development of friendships and independence?

Ashley: Yes of course. So, as I previously stated children with down syndrome could become emotionally attached to their 1:1 practitioner which can lead to an over reliance on them. This suggests that the constant adult present could prevent children from learning how to navigate social situations independently, relying on the adult to intervene or make decisions for them. As a result of this they may struggle to develop the confidence needed to initiate and maintain friendships on their own.

Holly: Great thank you, that makes sense now.

Reece: Also, can you explain how to support children with communication difficulties to be included in the classroom?

Ashley: Yes, so as I said earlier, a challenge with this is that the training for practitioners to support children with communication difficulties is limited and often at an unsuitable time, due to staff ratio requirements. However, to ensure an inclusive classroom environment, practitioners should invest time in learning Makaton signs themselves. By acquiring this skill, practitioners can effectively communicate with children who use Makaton as a means of communication, fostering better understanding and interaction. This proactive approach not only enhances communication between practitioners and children but also promotes a more inclusive and supportive atmosphere where children feel valued and included. As the curriculum for funded non maintained settings (2022, p.29) says communication is fundamental to children's development, meaning they cannot be discriminated against because of their additional learning needs.

Reece: Thank you.