Leave No One Behind in Education:
Including All Children and Young People

World Down Syndrome Day, United Nations New York, 21st March 2019

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Earlier this year I was invited to join speakers from around the world at the United Nations in New York on World Down Syndrome Day. Our subject was how to facilitate the teaching of people with Down’s syndrome of all abilities in an inclusive education system.

My brief was to outline the learning profile, make recommendations about how learners with complex needs can be included and to give examples of how inclusive practice has created opportunities and improved overall quality of life … all in just 8 minutes!

I chose to summarise practice developed over the last 35 years; to say how I thought learners with the most complex needs could also be included (they rarely are); and to raise awareness of our concerns about segregation from around the age of 14 years, which seems to be increasing.

I wish to thank Jake Binns for speaking about his preferences in a short film that completes the presentation. We thought you might like to see the presentation slides and accompanying words. Be sure to watch the film too.

“Learners who have Down’s syndrome have been educated in inclusive schools since the mid 1980’s in the UK; a long time. We know a lot about how to include learners in mainstream schools successfully and about the significant benefits for outcomes and employment from doing so.

Most learners who have Down’s syndrome start school at their local mainstream primary school, although some move to special schools mid primary. Far fewer learners progress to mainstream secondary school.

It is still not common knowledge among members of the public, the non–education workforce who support families or all teachers or education professionals that learners with Down’s syndrome do better in positive, inclusive schools.

We will now look at what has helped and what still needs to be done.

It has been beneficial for teachers to have knowledge about the ‘learning profile’ of common strengths, such as vocabulary learning, visual-spatial learning, reading, I.T., visual arts, and to know about aspects that may need support, such as working memory, verbal learning, speech, language and communication, motor skills, vision, hearing and autism, and, above all, to understand that learners needs are different.

We can provide information, training and many examples of resources that have helped children and young people to learn. Above are examples of visual and visual-spatial supports used to help learners engage, participate, record, follow schedules, and to support listening and remembering. The examples include manipulatives used during learning and writing guidelines that are bold enough for people to see.
But successful inclusion needs more than accessible lessons. Teachers need to know how to support friendships, transitions (changes), how to listen to the learners voice and respect their choices. They need to know they can find solutions, work collaboratively with each other and with parents, and they need to think long term.

There is also the question of how well teachers understand intellectual disability, particularly at secondary stage. In some schools it seems they may not, otherwise teachers would not make unhelpful comparisons with peers who do not have an intellectual disability. Instead, they would be celebrating successes and planning with young people and their parents for the next phase.

How can we create conditions for all learners who have Down’s syndrome to be educated at community schools, including those who have very complex needs, who currently are not included in mainstream schools in the UK, or not usually?

We can make more engaging, individual resources (can you see the picture of the coins in sparkly gel bag on the slide?) and teachers can further extend the curriculum, for example, to teach attention, communication and movement through a range of personalised sensory experiences, such as poetry, stories, songs, games, musical experiences and art.

Learners who have complex needs may learn in a variety of places and environments, not just in traditional classrooms. These spaces can be created in mainstream schools; there is no reason why they should not be.

But we will need teachers to understand the different needs of learners who have Down’s syndrome, as it has been our experience that when schools create separate places for lessons (e.g. bases, units) these can become the ‘go to place’ for learners who do not need these, who can be included in regular lessons and for whom expectations are too low.

In addition to learners with very complex needs not being included, we have seen an increase in restrictions for learners 14+ at secondary schools. We are seeing students barred from courses that lead to examinations they are not expected to be taking, placed in segregated classes instead.

I will now show a film of Jake, 15, who attends his local secondary school. He is planning for his future, thinking about what job he might do, and he is expecting to continue his inclusive education into his school’s sixth form. This is not a given, as most mainstream sixth forms currently exclude students who have intellectual disabilities; they don’t yet offer inclusion on their existing courses or suitable alternative accreditation.

We hope Jake will be listened to and his preferences accommodated, so he does not experience the loss of his peers, so that he is not left behind.”
“One of my biggest fears when Saajan was born was how he would fit in with the Sikh community”

Harp Kaur

When Saajan entered this world, much to our surprise, he came with a little something extra – he had Down’s syndrome.

My biggest source of guilt was that I’d wanted to give my eldest son a best friend. Instead it felt like I’d birthed a burden. My heart was broken.

Amidst all the confusion, chaos and grief, Arjun was falling more and more in love with his baby brother. He viewed the world through a clear lens … no judgement, no expectation. The things I tried to mask that told the world he had Down’s syndrome were the same things Arjun was cooing over, like his almond shaped eyes. Watching Arjun love Saajan unconditionally taught us. Arjun loves Saajan so fiercely and is extremely protective of his little brother. He’s also his greatest cheerleader and is so excited by the progress Saajan makes.

To say we were devastated is an understatement. The grief and shock that washed over me bought with it a wave of deep devastation as my mind was clouded with misjudgement. We grieved hard for those initial few days, weeks, months, for the perfect baby we thought we were going to have.

I was paralysed with fear as I was told that our lives would “never be the same” and that it would be “hard” by professionals who were basing their advice on outdated assumptions.

I was terrified. I wanted out.

What would our lives be? What did the future hold? What if he is a difficult child? Would he be a burden to Arjun, our eldest son? Would he live with us forever? Would we survive this?

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As time has gone on living examples of people with Down’s syndrome have squashed the outdated perceptions and fears that I had. I’ve learnt that people with Down’s syndrome can live independently and achieve so much given the right support – it may just take them a little longer.