It's not Rocket Science - it's Love.

By Sue Blackwell, October 2024

Excited, empowered, inspired by People who happen to have Learning Disabilities

Parenting is a challenge for everyone. Regardless of how well you prepare, it's one of those things you cannot know how you will respond until it happens. Then throw in learning disability. Compound that with negativity, stereotypes, professionals who apparently know what's best for you and your family, the system of bureaucracy, numerous laws of the land such as the Care Act 2014, assessments and reviews, computer algorithms where 'computer says no', and the 'panel' who have the power to determine all of our futures. These are just a few examples from the minefield waiting for you as you welcome your newborn to the world; a small person to be treasured, nurtured and loved as a valued member of your family, your community, an equal citizen of the world.

Malcolm and I believe every person is born equal with equal human rights. We believe in inclusion and equity. By default we embrace diversity.

So often societal norms prevail with professionals deciding who to sign to the parallel universe of life, BECAUSE a person happens to have a learning disability. We have only ever sought to support our children to live their best lives; to be happy, fulfilled and as healthy as possible. We have two children each totally different from each other, both requiring and deserving of appropriate support to become their own unique selves.

When people are happy living the life of their choosing they are less dependent on the system saving it huge sums of money over their lives. They are invariably physically, mentally and emotionally happier. As parents we believe we have the right to accept interventions which we believe offer the maximum possibility of enhancing the future of our children.

Jen was born with Down's syndrome. Throughout our textbook pregnancy and easy birth there was no inkling of any disability. After the first 5 hours with our new bundle of joy and in the glow of after birth I so clearly remember the registrar doing his rounds and looking sorrowful. He closed the curtains. 'Is this the baby you were worried about?' he asked the nurses. The bottom fell out of our world. Total shock and confusion. With no idea what to anticipate, 'Will she walk?' I asked. And so it began.

10 days later the diagnosis of trisomy 21, Down's syndrome was confirmed.

We kept being met with 'you can't', when Malcolm and I had always had the outlook of 'what's possible?'. Until we've explored ALL the options we can and learnt for ourselves, only then will we consider that we may need to find alternative paths. We were and always have been a close-knit team supporting each other through the ups and downs of life. Coming from different backgrounds, bringing our unique skills and love together we saw no reason why we shouldn't stay focused on what felt right for us and our first-

born child. We felt that we knew deep in our hearts what was best for our children and the family as a whole.

In our experience black holes have a nasty habit of opening up unannounced. Often seemingly inexplicably. Over the years we have come to understand that ultimately it will be left to us, the parents, to resolve tricky issues for which we invariably have no training. The bottom line is that we will always love our children. The professionals will, or can, only do so much. Then they clock off and go home to their families leaving you with the challenge unresolved.

For us, and well before the internet existed, we researched extensively, acquired and studied numerous abstracts with the help of the library before making the bold decision to fly to Detroit for 24 hours, when Jen was 5 months old, to see a medical doctor who had devised a vitamin therapy to help a developing body and brain, followed by close monitoring.

At 9 months we began a program of patterning under the watchful eye of the British Institute of Brain Injured Children. Gross motor stimulation to achieve neurological organization based on 'frequency, intensity and duration'.

This program and its frequent consultations provided structure in our lives for the next 3 years. Anthony was born into this routine and fitted right in, becoming totally engaged crawling and toddling alongside Jen whilst our 60 wonderful volunteers enthusiastically sang nursery rhymes, flashed flash cards they'd made in 3inch tall red letters, tickled trigeminal nerves, hopped, skipped or ran around the block. Each chose to gift 1 hour of their week to Jen. Unwittingly Jen had attracted her first community.

Where possible we chose to fit swimming, dance, gym, playgroup and music into our days, fulfilling the needs of each of us. With squash alongside the demands of work and family for Malcolm.

Every work move we have made was only taken after much research and consideration of the impact and opportunities it would create for each of us. At 9 years old one move saw us visiting 17 schools before deciding which village school would suit Jen and Anthony best. Every school option was researched with our list of questions for the headteacher knowing from experience what Jen needed to be supported to allow her to learn and develop. If it was right for Jen invariably it was right for the rest of us.

Jen has always danced. It's who she is first and foremost. From dancing down the aisles in the supermarket or the DIY store, to dancing around the kitchen table, dancing putting the shopping away and her unusual habit of making the floorboards bounce before bed. 10 minutes later she was asleep. Dance is in every fibre of Jen's being. She had to dance to be herself. She danced to tell us how she felt. Her speech improved through her ability to dance. She let out her frustrations through dance. Her language is dance. It's her absolute passion. When the dance stops it's a sign to be concerned.

When a special careers advisor said the local theatre could offer her a drama course, her immediate response was 'I want dance, not drama.' It felt as if she'd become one of

those hidden in plain sight at the age of 18. Outside of the system, yet beholden to it in so many ways, trapping her, and us in ways we could never have imagined. She'd become an adult and was ready for her next step, but the system couldn't cope with her mainstream aspirations to be a dance leader.

After 10 years of searching for suitable training for and with Jen we found nothing suitable. No-one understood, or was able to support, the needs of a dancer who happened to have learning disabilities. We attempted to work with a couple of dancers in different ways and also tried alternative living/caring arrangements for Jen to become more independent, but eventually she returned to our family home broken by the system. With no gainful daytime activity, no dance training or dancers in her life, and, in spite of a huge number of acquaintances, not one real friend, Jen was hurting badly.

That's when we knew things had to change and we had to take responsibility for making change happen. Out of pure frustration Jen, Malcolm and I set up DanceSyndrome putting a call out locally for other dancers with and without learning disabilities to join Jen in what we called Dancer Search Days to dance together, smile together and 'talk' through dance together.

We were overwhelmed by the response, showing us there were many more people searching for support to do things they loved. After seeing the smiles on their faces and feeling the joy in the room in those first five sessions, we had to take the next step.

The power of having something to get out of bed for

What we've learnt is that having something purposeful in the day fills each of us with a sense of fulfilment.

For over a decade, Jen's lesson at Flinders Dance School provided the most important 30 minutes of the week gifting her the reason to get up for. But leading a dance session is a whole new level of excitement and purpose that has led Jen to become a role model for others. When she's leading the dance she's in her element. She inspires others to try. The kindness and care she has learnt through discovering true friendship at the age of 28 through the group that came together changed the dynamic for all of us.

All through the power of having something to get out of bed for.

DanceSyndrome has grown and developed so much over the past 15 years. Just like parenting, we've learnt what doesn't work as much as what does work through trial and error. The organization offers people the opportunity not only to dance and move freely in a way that is available to them, but to learn to co-lead sessions if they want to.

We developed a unique training programme, Dance by Example, now accredited which covers life skills that help those who participate to become more confident in themselves. It has enabled some participants to apply for volunteer roles and part-time work, opening up new realms of possibility to those who desire and are able to take that step.

The Dance Collective, a group of dancers with and without learning disabilities choreograph routines that are performed on ever bigger stages. The responsibility and commitment these dancers, and their support, make to being part of this group is immense. The rewards are tremendous. Not just from the applause or the standing ovations, but from the smiles and joy on everyone's face at the end knowing they've done their very best and it made an impact on others. The impact is frequently tears of disbelief in response to the professionalism, and mesmerizing ability of all involved.

"Really lovely piece, very fluid, with lots of talented performers. As a parent of a disabled child, I was very moved and the performance brought me a lot of joy to see such talent."
Audience feedback, SENse, Edinburgh Fringe 2023

Our trained Dance Leaders volunteer to co-lead community dance sessions each week. They commit to routine and structure with extensive preparation which we've found brings improvement to all parts of life including communication skills, learning in all its forms, mental health and a deeper connection to a wider group, which the dancers call the Dancing Family. They are purposeful and are recognized for their skills and creative ideas as they work side by side as equals with professionally trained Dance Artists and other dancers. This affords the opportunity to inspire with each individual leading in their unique way bringing joy to others, putting a sparkle in the eye and a spring in the step. For people so often marginalized, to experience being in demand, feeling valued and contributing to society and the community you live in is a heady experience far outweighing any financial remuneration; being part of something outside yourself that makes a difference to other people is priceless.

Jen says, 'with the right support, at the right time, you can go further and further and further.' That goes for us as parents as well as those with learning disabilities. We ALL need appropriate support to get through the day. Finding opportunities with the right support enables each of us to feel fulfilled, expressing ourselves openly in our own language, thriving in our own life – whatever that means for each of us.

We had no idea how impactful this venture would be. From being written off at birth by professionals, our aspirational daughter is living her dream of being a dance leader, sharing her passion for dance across the world.

No one is more surprised by what's possible than us, her parents! Dreams really can come true!

November 2024 sees DanceSyndrome dancers with learning disabilities contributing internationally to training, conferences, projects and the Stevie Awards in the UK, Turkey, Spain, Japan and the USA. Jen (43) who now holds an Honorary Doctorate and a British Empire Medal for her services to disabled people and dance, tells us 'My disability doesn't define me. I'm proud of who I am.'

DanceSyndrome is a Beacon of Hope lighting the way for Social Change.

The Art of the Possible

Hand on heart, we know what's possible for people and families impacted by learning disability. Each of our stories will be different. But each and every person harbours within them a nugget of gold waiting to be discovered.

What we know to be true is that our determination, and probably our inability to accept no for an answer, has led us to this point where Jen is living behind her own front door, supported by an amazing team. Of her life Jen says 'I have the best job in the world. DanceSyndrome is my everything. It gives me a voice to be heard. It is my passion and my life'.

Jen became the tenant of a housing association age 30. With her new direct payment package Jen was now in control of every aspect of her life from daytime focus, living arrangements, carers and supporters (always with the caveat of 'with appropriate support'). Jen hasn't looked back. This arrangement has liberated her. It allows her to be her own person making her dynamic contribution to the world in ways we could never have anticipated.

Because Jen is happy and fulfilled and has a reason for living, Malcolm and I are free to live how we choose; actively nomadic rarely to be found longer than 5 days in any one place!

Tips from our experiences

- Follow your heart. Trust your gut instincts taking just one step at a time.
- Know your rights. And demand them
- When struggling go to the top. Knock on the door of the most senior people. And keep knocking. Don't give up
- Seek support from those you trust and respect. Use your networks to find people who can help
- Listen attentively and intelligently. Gift time. Read between the lines. Listen to body language.
- Check, double check and keep checking your understanding of the thing you're trying to figure out matches with the understanding of your loved one
- Knock on lots of doors. One will open.
- Behaviour out of character is a cry for help. Don't just hope it will go away. It won't.
- Use their preferred means of communication. Respond in the moment that suits them, not you.
- Tough love is imperative on occasion. For us, requiring and expecting socially acceptable behaviour from both Jen and Anthony was a given.
- Surround yourself with people who care and will lift you up when you are down, in a place of your choosing.

- Don’t necessarily take the easy route, hold out for what you believe is the right route.
- Celebrate, include, believe in the person you’re supporting. They have a unique contribution to make to society. They can teach the world to sing (or dance!)

Every day I am informed and inspired by people who happen to have learning disabilities. With the support of each other Malcolm and I have only ever sought to do our best as parents for each of our children. Every day I pinch myself! This is testimony to the power of listening to the person and believing in the art of the possible.

Watching people grow empowered through equality of opportunity and inclusion is our biggest reward. It is an immense privilege to watch people thrive as they develop their skills and individuality. We believe the 2% of the world with learning disabilities is a beautiful bountiful source of unique creativity waiting to be unlocked.

Life is for living. ALL our lives will be richer when we embrace, enable and empower ALL.

We support and believe Jen’s mantra – “Together, we can Dream, Believe, Achieve”. We don’t know what’s possible, but we can take the next step.