

## **Turning the world upside down**

What gives me, a humble musician, the right to boldly write a chapter in a book about successful women?

I've been on an extraordinary adventure these past 42 years with my family. We transform lives of people all too often forgotten by society. We turn perceived norms upside down. We have big ambitions to reach further and wider into every corner of the world.

I am a mum on a mission! I am indignant because the medics saw fit to write my first-born child off at birth. With no warning, after a textbook pregnancy, we were labelled a disabled family 5 hours after Jen was born. We were told she wouldn't amount to much and it would be best to put her in a home and forget about her.

But why shouldn't Jen have the same opportunities to be herself and share her love and talents with others? Just because she has Down's syndrome, why shouldn't Jen follow her dreams of being a dance leader in her community?

Why shouldn't Jen, and people with learning disabilities have access to support and encouragement to lead a life of their choosing and do what brings them joy in their lives?

I write BECAUSE of Jen, her dance, her focus and passion for life, and her learning disability. Unbeknown to me, Jen had already started making me my own person. As a natural introvert, Jen forced me to step up on her behalf, to be assertive where she wasn't able, to reach out to others and not be afraid to ask for help.

If you measure success financially, I'm not off the starting blocks having chosen to work as a volunteer for almost all my working life. If however we look at the legacy of our lives, I would be happy to be nominated posthumously for the yet to be coined 'Queen of Tenacity and Successful Actions' award, but only if open to joint applicants as it would necessarily include Jen, my award winning, decorated daughter, who happens to have Down's syndrome.

I'm told I think differently to most people. My default setting is to seek creative solutions to the multiple challenges life presents each and every one of us.

I invite you to believe in the possibility of creating a different society. One where every person matters, no matter who they are, what they look like or what their perceived abilities are. I believe everyone can contribute with joy in their life, to their family and community.

I want to challenge and change perceptions of what's possible for people with a learning disability or marginalised in some way. Often pushed around by systems which make no sense to those they are supposed to serve or those who work within the constraints of a checklist.

I know there's a different way from my personal experience of simply listening to my daughter. From her basic needs to supporting her to become the inspiring motivational speaker she naturally is, leading a multi-award winning charity; recognised in 2023 in the Kings Honours list for her services to disabled people.

The system sought to marginalise Jen from the off. We were referred to the Child Development Unit in the local town. I turned up to the clinical environment where Jen, just a few months old, was weighed, measured, 'assessed' and fussed over by other mums. Then a 7-year-old girl approached us with her tongue lolling down her chin wanting to cuddle Jen too roughly for my liking, followed by the loudest wakeup call I could possibly have received from her mum, 'she can't help it, she's got Down's syndrome'. At that moment if I didn't know it before, I knew I couldn't accept the status quo of a system that is fundamentally flawed and unable to serve each individual person all of us are.

Already actively searching libraries for knowledge and different thinking, at 5 months old we flew to Detroit to meet an alternative doctor working with nutritional therapy; at 6 months we visited the British Institute for Brain Injured Children, to learn more; at 9 months we embarked on a daily structured developmental program of cross-patterning BIBIC prescribed bringing support and order to our lives.

Starting with 3 hours a day, over the months and years the frequency, intensity, and duration of the activities transformed Jen from a person who could not move from A to B, to a person who could crawl up a six-foot-long ramp within three months. We were surrounded by incredible local people who volunteered to help with the daily exercises, who brought hope, inspiration and happiness to our home. This is the febrile atmosphere into which Anthony was born who joined Jen in the exercises, crawling, singing, laughing and having fun.

Later, after relocating, the local authority chose to steer Jen towards the special school in a different town, to be picked up and returned by taxi. They had a spare place they wanted to fill. We felt strongly that Jen had the right to be educated in her community, mix with others, pursue her interests in swimming, brownies, dance alongside others she knew from her village and school.

I've always sought to do my best as a mum, and from day one I never wanted to look in the mirror and say, 'I could have tried harder'. As Jen's parents we've found our way, step by tentative step, unsure and unclear, always listening to ourselves and our children. We believe each of our children is their own person and have always encouraged them to follow their dreams. Jen (42) is a dancer and musician, Anthony (40) is an engineer.

Perhaps now, we are experts by experience, but I prefer 'professionals'. As professionals we have an important contribution to make from those inauspicious beginnings. As a parent/carer we don't necessarily need to be the expert, but we

are the professional in the life of our loved ones. We know what feels right or when we're being pushed into something that ticks someone else's box.

Respecting and supporting each other to be the best that we can be, recognising everyone has equal right to contribute, every voice valid, and be involved with how they live and lead their life is fundamental to Malcolm and I. Practicing what we term co-production has always been at the heart of our relationship. We couldn't live any other way.

Our brand of co-production permeates all areas of our lives. None of the 4 of us would be living as we do without the support of each other, and without the support of Jen's dedicated care team or [DanceSyndrome](#). Each is a part of the whole system of support and won't work without the contribution, existence or support of the other parts.

I believe co-production happens naturally when underpinned by a bedrock of inclusion, and inclusion only happens when people are respected and valued for the person they are. That only happens when we learn to listen and communicate in a way that shows we are listening.

There is absolutely no point in sitting down with Jen for a serious discussion of any length without being open to interjections of dance. Whenever I hear 'Mum, can I ask you something?' or 'I know they're a special friend, but ...' it's time to down tools, to listen attentively to what's being said (and what's not being said), to be present in the moment, to gift the time to seek to help to find solutions through the challenge Jen is striving to unravel, but struggling to make sense of. And on those occasions when nothing seems to be working to recognize that sometimes you need to reach out to others - carers, family members, friends, or professionals - and that's ok.

Jen's dream was always to dance. She danced everywhere so it made absolute sense that this would be in her vision for her future. At the age of 18, an adult in the eyes of the law, the system expected Jen to pick up a thread with no support.

Age 21 a frustrated Jen threw down the challenge to us and society "I live for dance - it's my passion and my life. I have the right to a life of my choosing. My future lies in dance. I want to share my passion for dance and get the world dancing." 20 years on, Jen will tell you: "I'm living my best life in dance. My disability doesn't define who I am."

After 10 years of searching high and low we realised that the training we were looking for didn't exist. And that it wasn't only Jen who was being made to feel like they didn't belong in a society that saw people with learning disabilities as an inconvenience.

Nobody was offering exactly what she needed – an inclusive structured opportunity, spanning several years, where she could be treated as an equal and with appropriate support around her.

I remember the People Dancing conference in 2002 as a turning point. 200 plus community dancers confirmed that the training we sought didn't exist anywhere in the UK. We finally knew we weren't alone. It gave us license to be innovative and creative no longer facing rejection and closed doors. Those early days weren't easy. 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. Our charity DanceSyndrome was set up out of frustration with the system. Ten years on it is now also a multi-award winner, impacting the lives of thousands of people.

Without Jen there would be no DanceSyndrome. But without DanceSyndrome to support them, Jen and her peers would be casualties of the system; kept out of sight and out of mind.

At DanceSyndrome, diversity is the norm, inclusion is our bedrock - there are no barriers, hurdles to clear or glass ceilings to break through - everybody matters and has something to offer the conversation.

DanceSyndrome will always be grounded in the ethos that everyone matters. We are in demand. We are contributing to society. People are finding the support they need whether it's dance; a social outlet; a fun activity with a friend. People with and without learning disabilities, carers and parents are seeing what's possible for everyone.

Our unique business and delivery model is being recognised for the impact it's making. We're recognised as leaders of change, creating an impact wherever we go. We make a difference through our workshops and training programs across all sectors. At universities we get under the skin of undergraduates before they embark on their careers influencing and changing their perceptions and assumptions about people with learning disabilities delivering seminars they will never forget.

From being written off, Jen, her friends and support team, all co-contributors to DanceSyndrome make it look so easy! I won't tell you about the extra struggles we've faced because of our unique model of co-production. You know the ups and downs which are faced by anyone creating an impact and/or growing a business to make a difference in your community. Add learning disability into the mix and you'll get the picture.

Just imagine living in a world where discrimination doesn't exist, where every person brings their unique talents and assets to the table, taking from it what they need to nourish their soul, to flourish and thrive. Jointly we build the community of 'us', a place and space where everyone belongs.

I never knew what was possible until I challenged and turned things upside down. I know I've helped my daughter and son in their journey to become the unique people they are. Thinking differently is our norm as we live 'the art of the possible' through daily life and the strength and growth of DanceSyndrome.

We all have choices in life. Or do we? We cannot and shouldn't make assumptions of others. The choices I've made may be very different from the choices you've made, probably dictated by circumstances such as family issues, mental health, disability, age, illness, financial security etc. Our blinkered vision of learning disabilities gets in the way of allowing Jen to fulfil her dream. We assume she can't be the visionary she craves to be BECAUSE of learning disability so we don't give her chance.

If we pare it down to basics DanceSyndrome began with Jen's dream:-

**A dancer with learning disabilities craving equity** (*equality of opportunity*)

**A leader from unexpected places** (*diversity*)

**Including every person in the way that works for them** (*inclusion*)

**Wanting and needing the support of insightful others** (*co-production*)

**Sharing and contributing spreading happiness, joy and wellbeing in her wake** (*being human*)

Jen herself will tell you '**the best outcome of all is friendship**. I hadn't discovered friendship before DanceSyndrome but now I have friends in my life - people who value me for who I am - it's the most amazing experience ever!'

What's stopping Jen from fulfilling her dream? Learning disability or attitudes? Because she has learning disabilities she is deemed to be incapable of leading or contributing. Perhaps she might have found opportunities to work as an assistant or a helper with a dance artist but that wasn't what she wanted. She wanted to lead. Not only her words but her body language gave voice to this message loudly and clearly. Everywhere she went she engaged people in her dance with no verbal skills required. Jen's passion has shone through all her life.

So what can we do? What must we do? We can change the narrative - you, me, your next-door neighbour. We can step up, step over that invisible divide, embrace the human being within and discover what is important to them. Find out what that person is interested in, passionate about, intrigued by, or is incredibly good at - which might be sitting still - then harness their power imaginatively.

Open doors where they can't by themselves, walk beside them, allow them to reach you, listen, gift time, and before you know it you'll have a new friend who will intrigue you, empower you, guide you to new horizons, teach you things you'd never previously considered, and quite possibly you will have found a friend for life and new different opportunities to explore yourself. Your life will be richer BECAUSE of thinking differently.

My eutopia really does exist - a place where people are experiencing indescribable joy by simply being recognized for who they are - a human being.

Together we make a difference. We can transform lives and break down barriers enabling people to follow their dreams and passions, showing every individual matters. Turning things upside down creates possibilities and unexpected outcomes for everyone.

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