



# “If it needs doing...”

## Reflections on a decade of DanceSyndrome

In November 2022, North-West based inclusive dance charity DanceSyndrome was confirmed as one of Art’s Council England’s National Portfolio Organisations for 2023-2026. In February 2023, the organisation will celebrate 10 years as a charity. Here, **Sue** and **Jen Blackwell**, the mother and daughter duo who formed the charity, reflect on their journey and the barriers that they faced along the way.



Left: Pauline Hall, dance leader L, Jen Blackwell R, Performance, Royal Mile Stage, Edinburgh Fringe 2018. Photo: Rod Penn.  
Below: David Corr & Jess Reid, U Dance Festival, 2019. Photo: Brian Slater



“Exactly 20 years ago, in 2002, People Dancing’s Dancing Differently? in Manchester was the first conference we ever spoke at,” begins Sue. “Jen, just 21, had turned white as a sheet as we sat on the stage, clutching our scripts, awaiting our turn to speak. Jen shared her thoughts: “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 now tell you: “I’m living my best life in dance. My disability doesn’t define me for who I am.”

Jen happens to have Down’s syndrome. She went to a mainstream high school and when leaving school in 1999, she was determined that she wanted to turn her passion for dance into a career as a community dance leader.

It turned out to be a 10-year search for the right training and opportunities to follow Jen’s dream. 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 impairment. During this search, however, it became clear that Jen wasn’t the only person looking for such opportunities.

Sue recalls: “That People Dancing conference in 2002 was a turning point. 200 plus community dancers at the event confirmed that the training we

sought didn’t exist anywhere in the UK, so we knew we weren’t alone. It hugely expanded our network and, most importantly, gave us license to stop knocking on doors meeting eternal rejection and become innovative and creative.”

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.

DanceSyndrome was eventually formed in 2009 after Sue was given the helpful advice: “If it needs doing, just do it.” It was officially constituted and registered as a limited company. Funding applications were made to several organisations. The following year Jen advertised for dancers and got over 100 enquiries!!! She selected 14 dancers to work with, half of whom were learning disabled. Together they learned how to communicate through inclusive dance, meeting once a month for a full day rehearsal in Manchester.

2011 marked a pivotal point as DanceSyndrome began to trial our unique co-delivery method – a key factor in our success – with a learning disabled Dance Leader working collaboratively with a professional dance artist. In monthly sessions, the team worked hard to develop a toolbox of delivery techniques so any dance leader could successfully work with any dance artist, enabling everyone to be included and given the opportunity to lead. Funded by an Awards for All grant, more than 70 workshops were delivered in this way.

This dictated the way forward. 2012 saw the first regular inclusive community dance workshops >>



Sue and Jen Blackwell, Receiving Charity Champion Award. Photo: Joanna Cross.



Below: Sue Blackwell (L) and Jen Blackwell (R), Everybody Dance workshop. Photo: William Fisher.  
Below right: The Dance Syndrome Team. Photo: Julie Thompson.



delivered by these newly trained co-delivery teams. By 2016 DanceSyndrome had grown this provision to be delivering five of these Everybody Dance sessions in different locations across Lancashire and Greater Manchester.

2013 saw the constitution of DanceSyndrome as a charity on 14 February, a significant date because of the love and friendship that DanceSyndrome was already fostering. Important foundations were laid back then and our future success was to rest on the input of many people who gave up time, resources and money in those early days.

We made a good start. Just one month after achieving charitable status television comedian, actor and writer, Miranda Hart, and her camera crew visited rehearsals in the run up to a special performance for the Comic Relief Strictly Extravaganza.

Sue also recognised the impact that being fulfilled through dance was having on other aspects of Jen's life with the achievement of an appropriate direct payment package allowing Jen to purchase her care of choice and beginning to live independently as a tenant of Empower Housing Association.

Another change at this time, was the recruitment of a new DanceSyndrome Lead Artist. Performer/choreographer, Sophie Tickle had been working freelance for us and was offered the role of Lead Artist in 2013 and in 2021, she became Artistic Director.

Sophie has been integral to the success of DanceSyndrome. All the different opportunities we offer have been developed and refined by Sophie. She has a genuine intuition that allows her to understand individual needs and a caring nature that means she wants to enable and empower people to overcome any challenges and to demonstrate their abilities.

Also driven by Sophie, 2014 saw the introduction



of Dance By Example, a unique training course designed to give learning disabled people and non-disabled leaders/supporting staff the skills and confidence needed to co-deliver dance. This was a real success and many of the participants who were involved are still leading DanceSyndrome workshops or working with the performance team. The course is still delivered today and is now accredited at Level 1 and 2 by Sports Leaders UK.

Another first for DanceSyndrome, was a lecture and practical workshop on our ethos and methods for 3rd year Dance Performance and Teaching students at the University of Central Lancashire as

Left: Sophie Tickle, Artistic Director, DanceSyndrome.  
Photo: Nicola Selby.  
Below: Jen, aged 7. Photo: Sue Blackwell.



part of their community dance module. The students were clearly inspired at the end of the day and this led to future work with several universities in a range of different faculties.

This provision is vital to DanceSyndrome's commitment to changing perceptions of disabled people. Working with aspiring Dance Artists and future health and social care professionals before they start their careers encourages them to think about inclusivity without the bias that may already be established in some organisations and gives hope for a more inclusive future. This work also inspired DanceSyndrome's most recent professional development offer, Inclusive Approaches, training for established dance artists, who want to learn the skills to make their work more accessible.

Our unique, inspiring model has been celebrated with award after award, local and national, the most prestigious being the Queen's Award for Voluntary Service, in 2019, and the Prime Minister's Points of Light Award in 2018.

Speaking about these awards, Jen said "I'm honoured to have been nominated for not one, or two but three awards in 2022 and have won many different awards since 2015 when I was the Inspirational Woman of the Year at the EVAs! (This) shows that learning disabled people can do amazing things with their lives if given a chance. Dancing is my life; I am passionate about dance and about supporting people like me to have opportunities in the dance world."

Profile raising through winning awards translated into funding success with substantial three-year projects from both Spirit of 2012 and The National Lottery Community Fund. The combination of our courses seemed to work and all was going well for the charity, with inspiring performances at the Edinburgh Fringe Festival and National Learning Disability and Autism Awards and TV appearances too... then the pandemic hit.

The DanceSyndrome team quickly started offering free YouTube adaptations of every pre-pandemic session. These remained inclusive, adaptable, and professional, but they lacked the much-needed social interaction that everyone missed so much. Zoom sessions were the obvious solution and they were so popular that at the peak there were 15 sessions a week running, with innovative new styles like a rave-themed session being developed by the co-leaders. Finally, in July 2021, indoor dance sessions and live performances returned.

Online dancing enabled DanceSyndrome to reach beyond their physical location, breaking down more barriers than ever before! People from as far as South Africa, Europe and the USA were able to participate with truly inclusive dance for the first time ever, and they loved it – a real positive from the pandemic! In June 2022, the charity was awarded a second Reaching Communities grant from The National Lottery Community Fund to help them to continue offering both online and in-person sessions to empower people across the UK through dance.

Sue reflects that Jen's original vision is still relevant after so many years: "Fast forward 20 years from that first conference and DanceSyndrome continues to amaze us on a regular basis. It is fuelled by passion and determination. Learning disabled dancers lead the dancing family from the front. It demonstrates that no dream is too big if you approach it one step at a time."

She concludes: "Today I confess, I am the proudest parent! But I have the best teacher! Watching and learning as Jen/DanceSyndrome grow and thrive is an enormous privilege. The joy, happiness and confidence that exudes from this dancing family is palpable, virtual or in person, everyone is embraced. No-one feels left out in the cold, no-one is unwelcome, there are no barriers to participation, no glass ceilings. There is beauty in every movement."

#### Info

To find out more about DanceSyndrome, visit [www.dancesyndrome.co.uk](http://www.dancesyndrome.co.uk) or find them on social media @DanceSyndromeUK