



Choosing an Ordinary Life

Monique's Story



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Find me on
Twitter: [monabella135](#)
Instagram: [@monabella135](#)

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Foreword

I first met Monique in 2015 when she applied for a place on a leadership programme we were running for young disabled people from minority ethnic communities. 'Rights for All' was developed to nurture the next generation of leaders and Monique was a perfect candidate.

Throughout this programme and over recent years I have watched Monique blossom from quiet and uncertain to vibrant and outspoken. She is poised, principled and passionate and these qualities have lent a hand in defining the woman that she has become. Monique is spirited and brave, which motivates her to try new experiences, take risks and do the unexpected. This is something we have in common and have had numerous conversations about in coffee shops. Monique is multi-talented and this is demonstrated throughout her book.

She is her own boss and takes a no nonsense approach to disability, pushing boundaries and exploring every inch of what life has on offer. Monique is a people person and her ability to make and nurture relationships supports her in her pursuit to build and navigate an ordinary life that fulfils her ambition and desires.

I am delighted to welcome Monique as an Associate of Changing Our Lives and look forward to working together in the future.

Lucy Dunstan
Deputy Chief Executive Officer
Changing Our Lives

Chapter 1

My two educations

From a young age I knew that I did not want anything to hold me back in life. However, it took me some years to learn about myself and believe in my abilities.

I went to a special school for the first 15 years of my education. I had full access to all the services I needed such as Occupational Therapy and Physiotherapy, and opportunities to develop my interests in art, modelling, and photography. I was able to sit 5 GCSEs and do the Duke of Edinburgh award.

At the age of 18 I had a decision to make: I could either stay at the special school and go to their residential unit, or leave the special school and attend a mainstream college. If I stayed at the special school I would have opportunities to develop my independent living skills as this was something they focused on in the residential unit. They had a life skills room where all the appliances were accessible whereas at home the washing machine, for instance, is too low for me to reach.

Although I may have been able to develop my independent living skills at the residential unit, I chose to finish my last few years of education at a mainstream college. I appreciated the time I spent at the special school, but I felt it was more important for me to experience some mainstream education as this would help me transition to the ordinary life I wanted as an adult.

Whilst I was at the mainstream college I studied a Business Admin NVQ and Diploma. I faced many obstacles and struggles whilst I transitioned to this different type of education. It was harder for me to access the support I needed, for example I needed a scribe with me when I took exams to help me with time keeping and writing. Where in my special school this was automatically given to me, I found that in mainstream college the process of requesting a scribe was more complicated and time consuming.

Other challenges included accessibility around the college such as the doors not being wide enough for my wheelchair to pass through, and not always having the ramps and hoists I needed. I knew these things would be more challenging in mainstream college but until I actually experienced it I did not understand the reality of how this would affect my confidence. Most of my classmates were very nice and helpful, but there was the occasional person who would mock my abilities. Sometimes this was difficult but I learnt to laugh; especially when people thought that because they could walk this meant they could do better than me in assignments. I proved them wrong when my grades took me to the top of the class! I was happy to show everyone that I was able to manage in this mainstream environment.

“Starting mainstream college was like stepping into the unknown. Although there were challenges, it helped prepare me for what was to come when I became an adult.”



The skills I learnt from my Business Admin Diploma I am able to apply in my life. I now know how to submit invoices for my self-employed work, and also to arrange my own care package.

I continued to stay in contact with the special school and I am now a Governor there. I volunteer at the residential unit, helping the students through mentoring them and sharing my experiences with them. In particular, I talk to them about how I transitioned from being at a special school to where I am now having a career. I write reviews for the school and share my views with Ofsted each time they come in.



Chapter 2

My career

When I was 23 I took part in a leadership programme at Changing Our Lives called 'Rights for All'. We learnt some key leadership skills and had opportunities to visit Parliament and speak to people in leadership positions who were from Black and Minority Ethnic communities. I had a mentor who I met with for a year and he helped me develop my leadership skills.

I remember being very nervous when I first started this programme. However, I was encouraged to believe in myself and this is where I developed the confidence to speak out. I began to believe that even though I am disabled I am still entitled to live an ordinary life and pursue a career.





I knew I wanted a career as I would be bored if I stayed at home! I was approached for my current role as an Expert by Experience for the Care Quality Commission whilst at a delegate's event. They were looking for somebody who understood what it was like to live with cerebral palsy. They asked if I would apply for the role and go through their training scheme. As part of the application process I had to speak in front of 500 people! I spoke about how having this job would benefit my well-being as well as the well-being of the people using the services. I also spoke about how my direct experience could enhance my colleagues' knowledge. They were impressed with my speech which led me to being invited to the interview which I passed with flying colours.

I have now been in the role for 6 years. The role is perfect for me as the hours are flexible and I can pick and choose what I do.

I meet with people who have physical disabilities. I am given questions to ask them such as are they happy with the care service they are being provided with, and is there anything that could be improved. Although it is in a formal setting, I keep the interview relaxed and I ask open ended questions so they have the opportunity to share their experiences. I have found that because I am disabled, people speak more freely to me than to inspectors who are not disabled. If I am meeting people at a residential unit, I also observe how the staff are treating them and whether the kitchens are hygienic.

The job has widened my knowledge around mental health, physical disabilities, learning disabilities and looking after the elderly. It can sometimes be upsetting to hear somebody's bad experiences, so I have had to build thick skin. When I have a bad day I remind myself that I am able to help people and that is my goal. I am also able to speak to my employers when I have been affected by it and they are very supportive.

“ Having a career has built my confidence in myself and in my abilities. I am able to speak freely to others and I have delivered presentations! It keeps me feeling positive. ”



For all events, training days and inspections, whether they are paid or unpaid, I always make an effort because for me it is not just a job, it is a new lease of life. It makes life worth living to know that my experiences are having an overall positive impact on the people I work with.

I am able to provide for my family and I do not feel I have to rely on them just because I am disabled.

I love my new life as an Expert by Experience. I remember the first meeting I attended at a children and young people's advisory group. My group were deciding on names for a report we published on the experience of disabled people transitioning from school to college. The title we came up with was Lost in Transition. This still resonates with me as I do not want to get lost in transition again.

Chapter 3

My hobbies

Theatre



I first became interested in the theatre when I saw an army performance. The soldiers deal with their post traumatic stress disorder by telling their stories theatrically about their experiences of physiotherapy and recovery. Although I have not gone through the trauma that they have experienced, I am able to relate to the mental frustrations of having a physical disability. For instance, each morning and evening I am stuck until I have the support of a personal assistant, but I don't want to rely on their assistance.

I have been following this theatre group for a few years and I go to every one of their shows and workshops. I have built connections with the members of this group, and we have been able to learn from each other's experiences. Because I have had physiotherapy throughout my life, I am able to help motivate the soldiers to keep going when they start theirs. Even though life will not be the same for them, I can show them they will be able to get used to it and live a positive life.



I am now a board member for the theatre group and meet regularly with the choreographer and director Rosie Kay. She is my mentor and has been helping me to develop my solo piece.

Using the theatre equipment, I have created a short film for the BBC New Creatives called "I am Soldier" where I play a disabled soldier. It looks at issues such as post traumatic stress disorder and physicality. I was inspired by the poem "The Soldier" by Rupert Brooke. The poem pays respects to the fallen soldiers and paints a very realistic portrayal.

My film is available to watch on the BBC iPlayer now! (<https://www.bbc.co.uk/programmes/p08dn9kq>)

“ Meeting people who used to be able to walk but have had this taken away from them has helped me see the positives in my life such as being able to do my jobs and having the confidence to speak up. ”



“Monique never ceases to amaze me and I am so proud to call her a friend. She is guaranteed to light up the darkest of rooms with her energy and smile.”

- Bravo 22, a dance company I met during lockdown

“Monique impacts us by pushing us to grow and reach new heights.”

- AfroDesi, Dance Company



I was part of the Rosie Kay Dance Company's production of '120 Soldiers' that we performed at the 120th birthday of the Birmingham Hippodrome.

Sports

I have always been quite active and sporty. In school I was the only girl on the wheelchair football team. It was really fun and energetic - it was a bit like bumper cars. My wheelchair kept having to be repaired!

I struggled with my weight when I was at school but using my rowing machine at home has helped me become the weight that I want to be. I now use it almost every day, in the morning and in the evening. It helps to have music playing while I am rowing as this keeps me motivated. My favourite playlist at the moment consists of a compilation of afrobeats!

I also find yoga and meditation particularly good to release tension.





Chapter 4

My travels

My career has meant that I frequently travel in my work. This has increased my confidence in travelling in my personal life too, and I now frequently travel to India and Amsterdam to explore and visit my relatives.

I really enjoy travelling and I am able to book my own flights with the money that I earn from my job. I also arrange my own airline assistance. Sometimes it is time-consuming to prepare everything, but I am getting quicker at this as I travel more and more. I know what to expect when I travel now, so I know which wheelchair to bring and what equipment I will need.



India

I now travel to India twice a year. The first time I went was for my cousin's wedding. My relatives did not think I would travel to India because they believed it would be too difficult for me because I am disabled.

I was happy to prove them wrong and show people that I can do it! Although the transport is difficult because there are no seatbelts in the taxis, I have learnt to book in advance to request taxis that do have seatbelts.

I wrote about my special experience visiting the golden temple:

“ When I visit the golden temple I take my shoes off and put my feet and wheels in the water. The back entrance into the food hall is easier because people didn't have to carry me down the stairs, so the volunteers pushed me down the ramp. Waiting in the queue for prayers to begin, I am carried into the golden temple. Beautiful it is to actually sit and lay down; to put my hands together. My uncle and another volunteer carry me all the way in. It is difficult but I'm so grateful they are willing to pick me up so I can do my ritual. It is truly emotional and with happy tears I receive my blessing. I come back to England with a smile on my face and bursting out of my heart. ”



Visiting India is a chance to see my relatives and experience my culture. Each time I go I can refresh my Punjabi and enjoy the homemade Indian food that my relatives cook. I drink the Indian tea, wear my salwar kameez attire, and sing and dance to the music.

It is special to me to take part in the positive traditions of my heritage alongside my family.



“ Thank you, Monique, for the last 6 years of being your personal assistant. I’ve learnt so much from your drive to achieve and from your down days. I’m glad we got to experience travelling together before I left. From the spa nights to sightseeing and plenty of yummy food tasting, thank you for organising everything so smoothly. Be proud; you deserve it. ”

- Jaasmin, Monique’s personal assistant

Amsterdam

I recently travelled to Amsterdam and for the first time I stayed with my personal assistant in a hotel instead of with my family at my aunt's house. I wanted to be more independent this time.

At first it was hard to adjust. When I was researching the hotel it was hard to tell from the photos how accessible it would be. Although the staff reassured me it was wheelchair accessible, not all wheelchairs are the same.

My wheelchair and hoist would not fit into the bathroom so I had to have bed-baths. The wheels of my hoist could not fit under the bed so my personal assistant had to help me shuffle in.

I learnt a lot from this trip and now I feel more confident that I know what to look out for. The next time I went I made sure that there was a wet room with plenty of space, and a bed that was high enough for my hoist.



Moving around the city was great. Everything was in walking distance so I did not have to use public transport.

I loved seeing the art in the Van Gogh museum. I also visited the Heineken factory where they had recently installed a wheelchair route which included a stairlift, ramps, and accessible balconies.

All the exhibitions and displays were accessible to me. I could see everything properly, nothing was in my way, and everyone was polite. I did not feel disabled!

I was their guinea pig as I was the first disabled person to use their new equipment. I happily gave them a glowing report!

Being able to travel is a key part of my ordinary life. Although I have had obstacles to face both in travelling and in my career, I am conquering these every day and trusting the process. With each achievement I believe in myself more and more and grow in confidence.

I am excited to see what the future holds!



“ I am at my best when I’m busy. I like to keep moving. ”



**No one is too disabled,
or too affected by
mental health difficulties,
to live an ordinary life**

Changing Our Lives

Tel: 0300 302 0770

Email: ask@changingourlives.org

Web: www.changingourlives.org

Twitter: [@positive_lives](https://twitter.com/positive_lives)