



EMMA DURMAN,
KEYNOTE SPEAKER

THE WINDING
ROAD OF
WELLBEING:
POSTCARDS
FROM MY
JOURNEY



My name is Emma Durman, I am incredibly grateful to be here speaking to you today. I tend to struggle with what some people call 'imposter syndrome' - the feeling that there is always someone better placed, more intelligent, more qualified, more experienced than I.



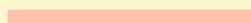
I do not know if that is informed by a lifetime of negative feedback, of complex trauma or just an inherent part of my personality - but the most important thing is that it means I will never underestimate the immense privilege and responsibility such a platform provides.



I have felt systematically disempowered throughout my life. I imagine many of you may share such feelings and experiences. In education, healthcare, employment, social interactions.



I am loud, sometimes unintentionally domineering, and I talk too much. But for much of my life it has also felt like I have been screaming into the abyss. To have been given this platform is incredibly emotional, validating, and cathartic. It says: "I see you. Your voice matters." For someone like me, that is an immeasurable gift.





Today is all about wellbeing. There was some debate about the title of the conference as it goes, because lots of Autistic people want to embrace and celebrate their Autistic identity – and so we should – but for lots of people, including myself, wellbeing can be an elusive beast.



It seems to slip my grasp like a willo-the-wisp, dragging me in circles and shimmering out of sight just when I think I'm finally on the right path.



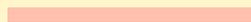
It was for this reason that we came up with the title 'Promoting Autistic Wellbeing': to celebrate it where it has been found, and to recognise that for others it feels still out of reach. To convey that today is about all the ways we can help ourselves find and sustain social, emotional, mental and physical wellbeing.



It's little wonder that wellbeing can be such a difficult thing to find and maintain for autistic people to be honest – most of us have spent our lives trying to conform, to survive in a neurotypical world, with neurotypical notions of success and wellbeing.



So even when some of us achieve the 'checklist successes' society tells us we should aim for, we may still feel adrift, confused, exhausted and unfulfilled.



 In a somewhat strange progression, western society seems to  have drawn more and more divides, made more and more little boxes and lost sight of the complexity of humanity.

 We separate mental health from physical health, social and emotional wellbeing from health altogether and place material attainments on a pedestal above all other, far more vital, far more precious commodities.

We need to take a far more holistic view. In a TED Talk I watched last year, loneliness or at least lack of regular social contact was the biggest indicator for mortality. Now what is regular social contact will differ drastically for everyone - and I truly understand and respect that.

 Equally, you could debate correlation vs causation on that study all you want but it feels true doesn't it? Humans are equipped with amazing resilience, an incredible survival instinct and such passion and curiosity. But what do any of these things mean if we feel alone? If we find ourselves without reasons to fight?

 More than this, we have pathologized normal human emotion. In another TED Talk titled the gift and power of emotional courage (yes, I really like TED Talks!) Susan David, stated, "Discomfort is the price of admission to a meaningful life."

 In these times of perfection, of Pinterest and Instagram lifestyles, it seems that everything needs to be perfect to succeed. How we look, who we love, where we work, what we do, where we live, how our home is decorated... the list seems endless. In all of this,  we have made natural human emotions like sadness, worry or loneliness a default negative in our endless quest for positivity.



This bleeds into the current narrative around disability too. Disabled people are either labelled as a drain on society, or as inspirational for 'overcoming' their challenges. We need to ensure there is space for the words 'I cannot'. Sometimes, acceptance of our limits can be key to a balanced and sustainable happy life.



I say all of this not in a spirit of negativity. I think that everyone should be given every chance and support to reach their potential. I just think that what is optimum for one person may not be optimum for another.



In yet another TED Talk (I know it sounds like a habit at this point) the concept of optimistic realism was discussed and championed, and it so perfectly summed up my view of the world: dream big and then ensure you work out the details.

Sometimes you may need to tweak and adjust your plans; sometimes you may fail; and sometimes all the failures lead you to somewhere you never knew you were always meant to go.

I'm going to talk a little bit about myself now.



I'm Autistic, and I have a rather long list of co-occurring conditions, including several autoimmune conditions which affect my energy and pain levels and thus impact all areas of my life.







I was diagnosed as Autistic late, after a lifetime of furiously struggling like a duck flapping madly underwater, and many different diagnoses that never quite fit the whole picture. I lived my life in a state of turmoil, looking around and wondering if I was just incredibly, utterly weak.



Everyone must face the same difficulties and yet they made it all look so easy. Why couldn't I just keep up. I felt like I was trying harder than everyone and still failing. I felt worthless, like the world would just be better off without me in it.

I had the intellect to contribute - everyone told me so.
Academically I was always quite gifted. During primary school I consumed books and knowledge ravenously. I loved learning, and exams.



If there are any Harry Potter fans here today, I was a typical 'Hermione'. Always asking questions and hand up jigglng in my seat desperate to give answers that bounced around my head. I was polite and well-mannered though very socially isolated. I just didn't fit in with my peers.



By the time I reached comprehensive school the increased demands of school life were taking an incredible toll on me. My immune system was struggling, and my fatigue was overwhelming. My mental health deteriorated until even the motivation to keep trying started to disappear.







I was diagnosed with anxiety disorders, depression and chronic fatigue. By the age of 13 I was housebound, often bedridden, entrenched in disordered sleeping patterns and suffering panic attacks.



I barely ate, with doctors convinced I had an eating disorder. I accessed education for an hour or two a week, via a home tutor provided by the local education authority. I was a shell of a person.



Eventually, after around a year and a half I returned to school part time – support was promised but failed to materialise. Luckily, I was able to catch up with my reduced timetable quickly, and left school with all 6 of the GCSEs that I sat.

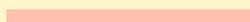


I went to college, to study A Level Psychology, English and Law. I did well but struggled to attend my lectures. I suffered daily migraines that were completely incapacitating.

Six months in, with many lectures skipped, my grades were still high, but my college mentor said that any of my chosen careers were impossible for me, as I would need to be able to attend consistently and my health meant I never would.



Disheartened, I gave up and quit education.





Thus, I began a cycle of obtaining jobs that I worked incredibly hard at and often did very well in, until I didn't. Burnout would creep up over and over, with me pushing myself until my life consisted of work and sleep, barely able to wash, eat and clean my clothes.

I would cut back on social demands and hobbies, desperately trying to keep up, until I would break, mentally, physically and emotionally.



I have been a Retail Supervisor; a Personal Assistant, both to a Senior Partner in a Law firm, and within the Chief Executive's department of the Local Authority; I have also been a Trainee Legal Executive. Jobs I loved and valued, that gave me value, and ultimately, jobs that I had to give up.



For me, the interview process was always easy. So were the application forms. It was maintaining the position that stung me every time. I didn't even know that I had different sensory, social and processing needs, so how could I begin to communicate what support I might need?



I burnt out over and over, a shaky recluse that existed in a state of anxiety, depression and isolation until I rebuilt my reserves. No-one could understand this. I couldn't understand this.





Finally, my partner and I became parents to our wonderful little girl, Mia. I knew that she needed me to be steady and consistent. I couldn't boom and bust any more.



I had to work for myself, set my own hours, be flexible around when I was well and when I wasn't. To embrace my periods of hyper productivity and respect my limits. It was the only way to stay well enough to care for her.

My daughter is also Autistic and has ADHD. She came into the world a perfect package of beautiful, smart, funny, kind, precocious and inquisitive. But more than that, she came with all the answers I didn't even know the questions to. 



She was a 'mini-me' - so similar to myself at her age, and she brought with her the knowledge and understanding that I was autistic and had ADHD too, a gift I can never truly thank her for. It has been empowering.

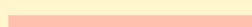
It enabled me to begin forgiving myself, a little at a time, for all the failures, the flaws, the struggles, and to re-envision them as resilient efforts in an inhospitable world.



All the wrong answers or partial answers fell away, slotted in, to a final cohesive whole.

My whole answer.

I am autistic.





It is said that disability doesn't define you, being Autistic doesn't define you. But I personally disagree. It does define me. It informs me, much as other aspects of my identity do.



Mother, partner, sister, friend, academic, geek, lover of cheese and Harry Potter enthusiast. All of them, and more, interweave to create the person you see before you.

There is talk of being bound by labels. Like they are some kind of trap that constrains you. This label freed me. It was everything.



It was all the ways I didn't fit. All the ways I didn't work. It was the silver and gold that binds broken pots, that makes them stronger, more beautiful than before.



It was sense, identity, understanding — of myself and the world.

It was acceptance, tiny but growing, of my flaws. It was a sudden realization that I was strong, am strong, not weak as the world had me believe. That I had not failed over and over, but had been failed, by the systems and supports meant to ensure I succeeded.



It was courage to find my voice, to use it. To fight for change, in my name, for all those after and before me. For my beautiful daughter.





My Missy, who makes me happy and frustrated and elated and so full of intense pride and love. My beautiful *mi amore* who is my love, my heart, my reason for fighting when I think I cannot fight a second more.



My daughter, who changed the way I see and experience the world, who gave me the greatest gift I could ever have hoped for and one I never expected: to finally know myself.

I am autistic. I am whole.

I've since embraced my Autism, the thing that informs every strength, every skill, every struggle and every weakness, to create what has already been an amazing career in a very short time.



Instead of holding me back, it has become the very thing to push me forward, to inform my practice, and to give me valuable insight into how we need to change things.

I am incredibly lucky, to have found a supportive business partner, who sees my strengths, value and talents and acknowledges my difficulties, struggles and limits, instead of dismissing either. Many autistic people find that either their strengths and autonomy, or needs and limits, are overlooked and ignored.



We need to get better at the balance that allows us to see both without negating the other. Limits shouldn't be taboo. In fact, recognising and respecting our limits, and pacing ourselves accordingly can be the key to a meaningful life, and optimum employment. Optimistic realism.





Recent achievements, like winning a Welsh Housing Award and speaking at an All Wales Counter Terrorism Conference, seem at odds with the version of me that struggled to get out of bed, to wash, to eat, to think clearly. But I am one and the same.

★ Imagine if we supported everyone like me to their fullest potential. Where would we be without doing so? Without Autistic innovation, invention. Without 'outside of the box' thinking.

Rosie King (oops yet another TED Talk) said, 'imagine if the best compliment anyone ever gave you was - you're so normal.' It wouldn't be much of a compliment.

We praise those that are unique, that show us a different way, that step outside the usual boundaries. Yet we somehow still place this huge effort into making everything and everyone fit these notions of normality.



Embracing our Autistic identity can be key to accepting ourselves and reaching our potential. Yes, it brings challenges for many of us - significant challenges for many. But let's not overlook the unique and intense joy it can also bring.



The ability to gaze upon a leaf in the sunshine and feel such a rush of happiness it takes our breath away. The ability to possess intense interests that light us up from the inside out in a way anyone looking can see - it is visible.

The animation, excitement and pure pleasure of engagement with our favourite topic that spreads joy is so infectious.





I am but one voice, one life, one story. 'Autism is a word trying to describe a million stories', as Stuart Duncan said. I hope mine will be useful, will provide depth and meaning to the wider considerations. But it is also important to remember that we need to listen to, and truly hear, a range of voices in our mission for true engagement, co-production and participation.



I do not dream of speaking for everyone – but I hope my voice will help carve out a space for the next – and that this will create a domino effect until all our voices are listened to, heard and valued.

Besides the differences in our life journey, in our experiences and memories and development paths, in those who support us, or who fail to, or who influence our thinking, there is also the intersectionality of health, gender, race and sexual orientation that impact the diversity of our neurodiverse community.



We need voices from all perspectives, backgrounds and beliefs to truly form a full, encompassing picture.

UN Secretary-General António Guterres said:

"On World Autism Awareness Day, we speak out against discrimination, celebrate the diversity of our global community and strengthen our commitment to the full inclusion and participation of people with autism. Supporting them to achieve their full potential is a vital part of our efforts to uphold the core promise of the 2030 Agenda for Sustainable Development: to leave no one behind."





I feel that is a tall order in little over a decade. We already know many of us are left behind, pushed to the fringes of society, with the next generation of children and young people facing the same barriers and inequalities I did decades ago.



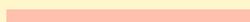
We have reasonable adjustments starting to be made slowly – some great first steps, but they are not enough. You would not tell a wheelchair user they could access the lift for only one hour a week, and cognitive, sensory, communicative accessibility should be no different.



Our children are still facing huge inequalities in education – and as a community we have higher rates of housing difficulty, homelessness, difficulty obtaining and sustaining appropriate education and employment, self-harm, suicide, healthcare disparities and mortality. Indeed, all of the wider determinants of health that make up the world health organisation rainbow of indicators of overall wellbeing.



Despite this – we find the onus is often firmly placed on us to change. To fix ourselves. To adapt. To fit in. But we are not broken. We are not a collection of deficits. We are complex, beautiful, intricate beings with individual profiles of strengths and weaknesses, just like the rest of humanity.





We cannot be boiled down to simplistic, reductive, harmful, functioning labels, that often mean some get their strengths and autonomy ignored, while others get their difficulties and support needs overlooked, in a medical model that does not account for the impact of social, environmental factors on functional ability.

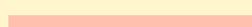
That measures based on 'how functional do I look to you', failing to account for the internal experience that may differ drastically in those of us who mask or camouflage. That functioning can differ drastically moment to moment, hour to hour, day to day, or indeed throughout the life cycle, affected by stress, transition, bereavement, alterations in support, relationship breakdown, menopause and aging.



With this in mind, we need to think about the lessons we can take from the social model, now over three decades old. That societal barriers drastically impact the level of disability that any individual experiences. I once read an incredible analogy that described this to me perfectly.



If you take a saltwater fish, and place it in a freshwater fish tank, it will inevitably struggle. It may float on its side, struggle to swim, possibly even die. But it is not the fish that is faulty, it is the environment that is inhospitable. If you were to reverse this and place a freshwater fish in a saltwater tank, the same results would occur. Autistic people are just the minority fish in this equation.





Damien Milton, an esteemed Autistic academic wrote about the 'double empathy problem'. This suggests that rather than labelling Autistic people as the ones with deficits - we need to meet in the middle.



If I were to go to Germany, I would not term the Germans as broken or defective because I could not understand their language. I would try to learn some simple phrases, maybe find a translation app, or hire a translator that could speak both German and English to help me.

Likewise, if you asked non-autistic or neurotypical people to understand Autistic people - to socialise in the way we do, to coexist in the way we do, they may well struggle also. Instead of 'deficit' we need to see 'difference' - and to move the responsibility onto neurotypes to make adjustments.

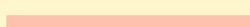


Even when we get it right, in terms of understanding and support, we sometimes then go on to get it wrong. We treat Autistic needs for accommodation and adjustment quite differently than we would for lots of other conditions.



For example, if you were to go to the opticians, and find your needed glasses, when those glasses worked and you were now able to see clearly, to read and write with ease, we would not then say, the glasses have worked, lets reduce the prescription or remove them altogether.

But so often this is what we do with support for Autistic people.





Don't get me wrong, I believe in fostering independence wherever possible. But for some people perhaps the goal of autonomy is more important. To be able to say, 'I cannot manage travelling alone, but I am good at X, Y, Z' and get the help with the travelling to accomplish the rest, may be the key to us living our best lives.



I think that people are aware of Autism now. Awareness is a word that now sets off an involuntarily visceral reaction in me. Awareness is not enough.

We need to build upon that, to acceptance and understand. Kieran Rose, a well-known Autistic advocate put it brilliantly, saying 'Awareness is passive, but acceptance and understanding is active'.



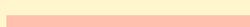
That is what we need. Active allies in the battles we face every day. With the support of those who love us, who care for us. With the support of policy makers, service providers, political representatives, educators, we can win this war faster - with less casualties, less trauma.

We need allies. Allies who will listen, reflect, and amplify our voices, stand with us, take sledgehammers to the walls that face us every day.



Everyone has a role to play.

Together we can make the pendulum shift. This is a call to arms.





It is my deeply held hope that every barrier we break down, every misconception we challenge, every battle we fight, every obstacle we overcome will be one less for the next generation of Autistic/neurodiverse people to face in the years to come.



I want to thank you all, all the Autistic people here and in the wider community, wider world. My tribe, my neurosiblings, my place where I finally fit, that I can call home. Like an invisible web so many of you strengthen me, weave into the tapestry of my work and activism, drive me forward even when the world feels overwhelming and impossible to navigate.

Like stars that were hidden from view in an endless night sky  my diagnosis has given me the lens I needed to finally to see you all there where you always were, twinkling, dazzling, incandescent sources of light and warmth.



I want to end on this note:

There are some lyrics from a Garth Brooks song that I often hear in my head:

"I hear them saying you'll never change things,

and no matter what you do it's still the same thing,

but it's not the world that I am changing -

I do this so - this world will know, it will not change me."





This still resonates with me often, but now I do hope, to change things.

If you cannot change the world, change one person's world.

The ripple effect is real and tangible and everything we do matters.



I call on you all now to create ripples, splashes, waves until we combine into a tsunami of change.

One drop of water may not change the tide, but when we combine each and every drop of water we become an unstoppable current.

