

Peace Pathway Conference  
Presentation by Emily Nuttall  
Lived Experience of Autism and Anorexia



# Introduction and Who am i



**Im a woman who has overcome adversity and all about empowering people, inspiring long lasting change, removing my masks, revealing the brave, bruised. real Emily and growing in recovery.**

**Im an abuse survivor, have overcome traumas, family breakdowns, violence, domestic violence, homelessness and other challenging, painful life events.**

**I have an anorexia diagnosis, autism, other co-morbidities including self harm, depression, ptsd, anxiety, suicidal thoughts and a range of physical disabilities, medical challenges but these do not define me I am still Emily**

**Im an EBE in autism mh eds other education hsc services in my local area overseeing projects, treatments, services and delivering training to everyone. I am working towards becoming a counsellor I2 completed I3 in future, also a speaker, author, volunteer, making a difference everyday with various national and local charities and services who I work with which include Beat, Maudsley, Kings, Freed and Peace Pathway to empower and inspire**

**I want to now share some of my autism and eating disorder journey with you**

# What is some of my story of having autism and anorexia



- ▶ I was first diagnosed with Anorexia in August 2008 aged 12
- ▶ Suffered silently and secretly for 3yrs prior to my diagnosis was a way of coping, escaping and control also diagnosed with other co-morbidities such as PTSD, depression, suicidal thoughts, self-harm and anxiety
- ▶ Initial assessment for autism diagnosed and recognised at the age of 13 but nothing really came from this diagnosis other than Asperger's and my treatment didn't change and I experienced 4 traumatic CAMHS medical, inpatient and outpatient treatment support
- ▶ Further assessed for a full comprehensive autism assessment in October 2017 in adult services aged 23 after 2.5yrs after having challenging, traumatic eating disorder inpatient and day patient treatment before being diagnosed with autism 2 months later (high functioning)
- ▶ Anorexia and autism has been a way of masking and coping with all areas of life, trauma, pain, hurt, abuse, violence, disabilities, medical conditions, family breakdowns and managing life and overwhelm that presents with it
- ▶ now under a specialised disability, autism and eating disorder treatment service locally in my area and working with other services which has truly empowered my recovery

# What helped me and still helps me in eating disorder treatment and how has my autism diagnosis has benefited this



- ▶ **The importance of building routine and giving notice for any change as early as possible this helped me to feel prepared and engaged**
- ▶ **Consistency with care, treatment and support from the professionals involved in supporting me meaning I wouldn't have to share my story again and again and not become traumatized**
- ▶ **Shared systems for sharing information within the mdt autism, medical and eating disorder teams so that everyone knew what was happening**
- ▶ **Creative and alternative therapies and having things available to ground me and feel safe and bringing items to treatment that helped to support me, express and cope with treatment**
- ▶ **The importance of the environment my treatment was taking place in being adapted as much as possible – the blank canvas exercise with each individual – I will share a bit more on this**
- ▶ **For seeing me as Emily and not as an autism and anorexia diagnosis and no other labels for my other struggles and diagnoses, walking alongside me, believing in me and instilling the hope of recovery**
- ▶ **Having back up plans and prevention plans to manage relapses and blips and how these help me**

# What didnt help me in treatment and how has this affected my autism, anorexia and other struggles



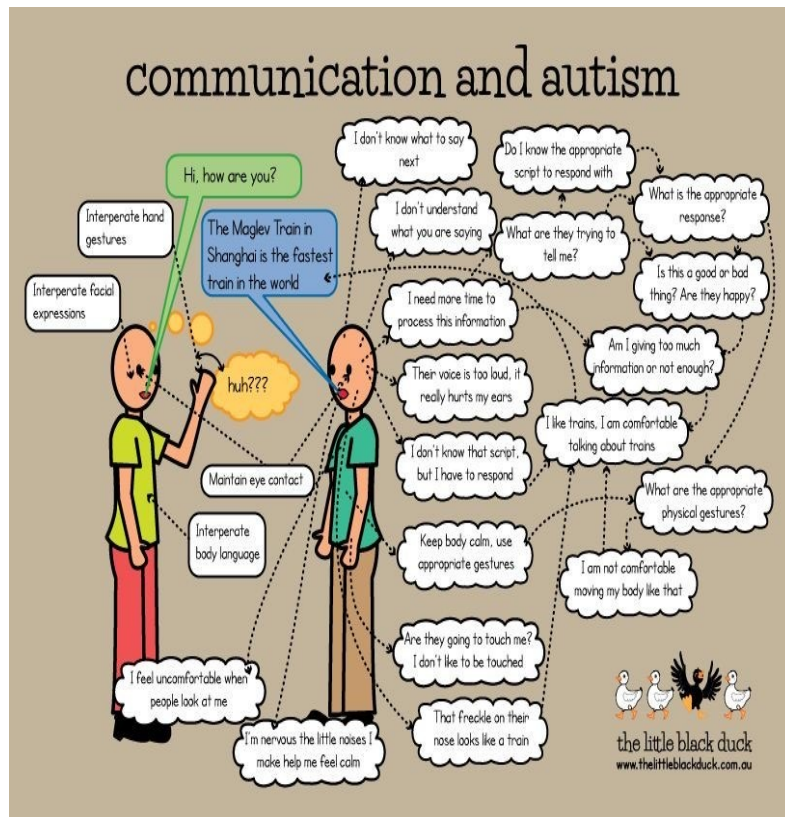
- ▶ **Clinical environments and sensory experiences.** A lot of my inpatient, day-patient and medical environments were often very bright lighting, looked like an inclusion room, hard flooring and be very echoey, have medical smells and would make me distressed and overwhelmed and as a result go into sensory overload
- ▶ **My treatments such as cbt, dbt, mantra therapy, other talking therapies not being adapted effectively and often very rigid in how the treatments would have to be carried out and where they had to be carried out and if I didnt follow that process I would be considered as non-engaging, it would make me very overwhelmed and shut down to treatment and caused me to feel shame and anger, or if the right treatment wasn't being offered I would stay stuck in the same place and sometimes it was an all or nothing situation so would then be discharged without support for not making progress in expected time frames**
- ▶ **Any expected or unexpected changes to treatment not being effectively communicated to me would often make my distress and behaviours more intense so that io could hold on to a sense of feeling safe and in control in another way, which could often mean id fall back quite quickly, become more anxious, shutdown to myself, everything and everyone**
- ▶ **Trauma would then like to be caused and resurface and worsen making the autism harder to manage and the ED to worsen as a way of trying to escape the trauma**

# The importance of the treatment environment for autism and eating disorders



- ▶ **The importance of thinking of each new service user as a blank canvas – what do I mean by this ? And the use of open questions**
- ▶ **The 54321 grounding techniques ( 5 things you can see, 4 things you can hear, 3 things you can touch, 2 things you can smell and 1 deep breath) when thinking of the treatment environment and how does this work and help those with autism and eating disorders and how this helped me**
- ▶ **Toolbox building to layout and adapt treatment rooms for autism and eating disorders what does this look like?**
- ▶ **The importance of being individualized, creative and adaptable as much as possible**

# The importance of communication and the holistic approach with eating disorders, autism and other co-morbidities, what are some of the differences, positives and difficulties in treatment



- ▶ **1. Verbal and non-verbal communication to engage**
- ▶ **2. Speaking, reading, drawing and writing in treatment and use of communication cards and boards and treatment passports**
- ▶ **3. Understanding verbal and non-verbal cues in treatment the positives and negatives**
- ▶ **4. Cultural differences and languages in treatment how this could be a challenge for me**
- ▶ **5. Body language, facial expressions and hand gestures how I managed and didn't manage this**
- ▶ **6. Getting lost in interactions or misinterpreting, not breaking things down, too many people involved at once**
- ▶ **7. The holistic approach when treating eating disorders, autism and other co-morbidities how to treat them separately and also bring them altogether to treat the 'whole person' and the empowerment this can bring**
- ▶ **8. What helped me and didn't help me with these processes in treatment and the hierarchy of needs**

# Creative and alternative therapies to treat autism and eating disorders and how this helped me



- ▶ **Play based therapy**
- ▶ **Art therapy**
- ▶ **Music writing, singing and playing instruments**
- ▶ **Lego therapy**
- ▶ **Dog therapy**
- ▶ **Journaling and poetry**
- ▶ **The use of fidget toys**
- ▶ **Mindfulness and Yoga Mind and Body Connection Therapy**
- ▶ **Food exposure therapy alongside creative emotional sensory therapy**
- ▶ **Communication and Vision Boards**
- ▶ **Worry balls and Worry worms**
- ▶ **Traffic light systems**



# Masking with autism and eating disorders



- ▶ **Masking is common with autism and eating disorders as a way of feeling safe and feeling less vulnerable**
- ▶ **Wearing this mask of “I’m fine” has blocked out distress, fear, trauma, flashbacks, health challenges, voices, devastating life events. It has guarded me from the pain, protected me from people’s judgements, actions and hurt, given me control, completely numbed me and been a way to be able to disconnect and forget, but yet still be this strong, smiling, determined, thriving, giving, achieving Emily for everyone around me in my life.**
- ▶ **But underneath this mask has been so much more. Depression, anxiety, self-harm, suicidal thoughts, PTSD, autism, flashbacks, voices which then led to anorexia had consumed both my mind and body in a terrifying and frightening way, but it was also like they were my best friends that I never had the comfort, the safety blanket and coping mechanisms I desperately needed, something that was there for me, that would help make everything feel ok and get me through the trauma, turmoil, fear, pain, devastation and loss of control that life had thrown my way. This made it so much harder for me to be open and accepting of help and support, which prevented me accessing treatment. I felt a lot of guilt and shame for being Emily.**

# Removing those masks



- ▶ **“For autistic individuals who have eating disorders to feel, heard, understood and succeed in this world, they need to find their strengths and the people that will help them get to their hopes and dreams. In order to do so, ability to make and keep friends is a must. Among those friends, there must be mentors to show them the way. A supportive environment where they can learn from their challenges and grow on their journey of recovery and feel a sense of belonging is what we as a society needs to create for them.”**

**Bill Wong Autistic Occupational Therapist**

# What roles do I do now from my own lived experiences



- ▶ **An expert by experience for the States of Guernsey Adult Disability, Autism, Mental Health and Eating Disorder services delivering projects, training, equipping and adapting professionals and services and working with London trusts, also completing my counselling training to make a difference in the future**
- ▶ **Helped to adapt Mantra treatment to help treat anorexia and autism with Jess Griffiths**
- ▶ **Delivered neurodiversity and eating disorder training to Orri an eating disorder day programme based in london and delivered training to their online services**
- ▶ **Delievring webinars and speaking at conferences and delivering training to Kings College and the Maudsley**
- ▶ **Been part of the EDAC workshops to improve outcomes for autism and eating disorders to find a better way forward and improve research**
- ▶ **Working with the EDCRN and Beat the UK eating diosrders charity to share lived experience and empower research and speaking at future events and conferences and delivering training**
- ▶ **Open to other opportunities to empower and inspire long lasting change**

# My involvement with peace pathway



Pathway for Eating disorders and Autism  
developed from Clinical Experience

- ▶ **Joined in January 2023 and has empowered and inspired me**
- ▶ **Overseen new interventions to help treat those with autism and eating disorders**
- ▶ **Helping with the purrble project and sharing of other sensory toys that I have helped to build and develop in my services to treat children, young people and adults with autism and eating disorders**
- ▶ **Building and exploring webinars, training, other conferences and projects to empower and inspire long lasting change and bring collaboration and connection**
- ▶ **Dissemination of the PEACE Pathway in the Community and Specialist Eating Disorder Services**

# Growing on this recovery journey with autism, anorexia, other challenges and going forwards and where am I now?



- ▶ **Autism, Anorexia and other challenges and life recovery for me is best described as a roller-coaster journey full of ups, downs, twists and turns, loopdaloops and abckwards drops healing is never a straightforward path**
- ▶ **The importance of being my own compassionate loving best friend every single day**
- ▶ **The importance of self care and self compassion**
- ▶ **Being brave, bruised and vulnerable**
- ▶ **The reminder that by being different we can succeed together**
- ▶ **How self-awareness helps me every day to be aware of changes, difficulties, warning signs and reminds me of what skills and tools to use for support and to keep going and growing everyday and to remind myself and others with autism and eating diosrders to nevr be ashamed of our stories as it will empower and inspire others**

# Final thoughts, quote, questions and connection and thankyou for coming



- ▶ See each individual with autism and eating disorder for more than their illness or struggles and individualize their care, treatment and support
- ▶ Never give up hope or belief that someone like myself with autism and eating disorders are not recoverable. We are recoverable and we are worthy of care, compassion, treatment, opportunities and support
- ▶ I would be happy to collaborate together to equip, train, grow, empower and inspire long lasting change for the better connect at [emily@cwgsy.net](mailto:emily@cwgsy.net)
- ▶ Finally myself and everyone with autism and eating disorders need to know We are brave, we are bruised, we are who were meant to be – this is them and me- Thankyou for listening today