The Elephant in the Room

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Autscape 2018
Introduction

• This is a talk exploring why some autistic people aren’t recognised (aka diagnosed) as autistic in childhood

• Using sustained metaphors and allegories to explore types of avoidance and bias at play

• Then considering how these factors can also affect autistic people with other disabilities, chronic illnesses or neurodivergencies
About Me

• I didn’t access an autistic spectrum diagnosis until 2012, age 32

• Before that, dyspraxia in 2007

• I’ve since been diagnosed with Sensory Modulation Disorder and ADHD (Inattentive type)

• I have a ‘hidden’ physical disability

• I’m not a researcher or an ‘autism professional’
“The elephant in the room”
“The elephant in the room”

- An idiom for avoiding a difficult truth
- *Pretending not to notice the large and obvious inconvenient fact that no one is comfortable acknowledging or mentioning*
- This can work as a metaphor for avoidance often shown by the adults in an autistic child’s life, which might delay recognition, access to services, SEND accommodations etc
“We don’t want to label him”

• Before accepting neurodivergence, people in the child’s life might actively look for ways to avoid acknowledging the ‘elephant’

• “We know she’s a bit different, but that’s just what makes her the unique person she is”

• “We don’t want to limit him with a diagnosis”

• Teacher: “Autism’s controversial and upsetting, it’s not our place to suggest this to parents”
The elephant from within the room

• The “elephant in the room” metaphor plays on how an elephant’s size would be unavoidable; they’d rub against you, knock over furniture

• Even if you’re not mentioning the elephant, it’s presence is obvious from within the room

• Parents, caregivers or teachers of an autistic child are in the room with their ‘elephant’

• Even without naming it, they know something is there, they know its shape and size
The Parable of the Elephant

Image – romana klee, flickr
The Parable of the Elephant

- Dates to at least the 1\textsuperscript{st} Century BCE
- A group of people examine an elephant, they’re either blind, blindfolded or in the dark
- Each feels only one part of the elephant and confidently declares it’s some other object
- The legs are tree trunks, the tail is rope, the ears are a fan, the tusks are spears, the trunk is a snake, the body is a boulder
The Parable of the Elephant

Image – Nat Titman
Diagnosing an elephant

• Imagine our blindfolded people as different types of experts, all trying to ‘diagnose’ the elephant

• Each *specialises* in their own area of the body

• **Not one has successfully diagnosed ‘elephant’**

• The original parable often ends with the different people comparing notes and realising they need to work as a team to understand the elephant as a whole – *if only more specialists did this!*
The elephant through the door?

It’s hard to get an elephant into a doctor’s office, only one part can poke in through their door

Image – Baron C. de Grimm, Project Gutenberg
The elephant through the door?

- Experts rarely spend long enough with a child to be able to see the ‘whole elephant’
- Specialists in different neurodivergencies rarely work together or compare notes
- They never get to see the entire ‘elephant’, only the fraction that fits into their office
- Each only finds the fan, the spear, the snake, the rope or the tree trunk that fit in their door
From metaphor to case study

• Imagine you’re an undiagnosed but highly verbal autistic child who could be diagnosed with all sorts of other overlapping conditions.

• Think about the shape that your ‘elephant’ might take, and how many different parts there would be to it.

• Consider which type of expert might be the first door your ‘elephant’ peeks through...
Scenario 1: Learning difficulties

• You’re mostly seen as very bright, but you struggle with one aspect of your school work

• Maybe you always score poorly on spelling tests despite reading and writing well

• Maybe you can’t learn your times tables, or your mental arithmetic is extremely poor

• You may be sent to an educational psychologist who diagnoses dyslexia, dyscalculia or specific learning difficulties
Scenario 2: Sensory issues

• Perhaps you’re very sensitive to loud noises
• You complain about flickering lights that no one else can perceive
• You refuse to take part in sticky or messy play
• You can’t stand how clothes feel on your skin
• You could be sent to an occupational therapist who diagnoses hyperacusis or a sensory integration / modulation disorder
Scenario 3: Hyperactivity

• Perhaps you’re seen as loud and disruptive in nursery school

• Or maybe they notice you have difficulty following instructions in primary school

• Perhaps you ask so many ‘silly questions’ that your teacher assumes you can’t be sincere

• You could be given an ADHD diagnosis first, or possibly even a conduct disorder
Scenario 4: Coordination

• You can’t yet catch a ball, ride a bike, whistle or tie shoelaces when your classmates all can

• Perhaps you’re weaker and less coordinated than anyone else in PE classes or during craft activities

• Maybe it’s your handwriting and improper pen grip, your inability to use a fountain pen

• You might get classed as having dyspraxia, Developmental Coordination Disorder, perhaps Nonverbal Learning Disability
Scenario 5: Anxiety

• What if instead of being labelled, you start to become extremely anxious

• Perhaps you show signs of compulsions, follow rituals to avoid disasters happening

• Or you believe everyone hates you, is out to get you, that every laugh is about you

• You might be diagnosed with some form of anxiety disorder or obsessive compulsions
Scenario 6: Social / Emotional

• Maybe you have very naïve or unusual beliefs

• Or get much more upset, or more enthusiastic and animated than most kids your age do

• Perhaps you act very childishly, and have ‘age inappropriate’ interests that lead to ridicule

• Or you copy other children to get by and so act wildly different in some classes to others

• This may be misinterpreted as emotional issues, a personality disorder, even atypical psychosis
Scenario 7: ‘Gifted’

• Or maybe everyone focuses on how you do extremely well at some school subjects

• You talk to teachers like you’re another adult, a little professor or philosopher

• You take your hobbies so far and practice so intently that you’re seen as a prodigy

• Maybe you’re labelled as gifted, or even with ‘Gifted Child Syndrome’ where emotional skills lag behind intellectual development
How would it really go?

• Not every specialist our case study kid might see will understand the pervasive, overlapping way that neurodivergent conditions affect our lives

• Educational Psychologists, Occupational Therapists, etc often don’t know the spectrum well enough to look out for ‘autistic elephants’

• Specialists might come to interpret the number of ‘undiagnosed elephants’ being squeezed into their offices in a different way...
The *tree trunks* in the room?

“I knew this was a tree trunk as soon as I heard the trumpeting coming from the waiting room”

“It’s not strictly in the diagnostic criteria but, as an expert, **you start to start to recognise non-clinical symptoms** of tree trunkism”

“In my professional experience, tree trunks come in fours, and with many other **comorbid conditions** – particularly spears and fans”
Not so hypothetical

• *Surprise!* I was that hypothetical highly verbal undiagnosed multiply neurodivergent child

• All those scenarios described different traits I showed that meant I stood out from my peers in different contexts or at different ages

• *So what did I really get diagnosed with?*

• *What part of my elephant was the first to poke through a specialist’s door?*
It was the tips of my toes!

• In real life, the thing everyone was most concerned about was that I was still walking on tip-toes at the age of 6

• I was sent to a consultant pediatrician who diagnosed achilles tendon contractures

• A physical, *measurable* problem with the tightness of my heel muscles!

• *Eureka! The search was over!*
This explains everything!

• Other difficulties were ignored for a while – after all, I was being seen by an expert

• Eventually I had heel surgery to lengthen my tendons, followed by physiotherapy

• And so every problem was covered by my legs – or by the school work I’d missed being in hospital – or by not being able to do PE for a year, etc etc

• Why look for anything else?!
The elephant under the rug

Image – Nat Titman
The elephant under the rug

• Having only *part of your elephant* named can make it harder to get help for the rest

• We’re back to avoiding the elephant in the room, but now we have a name to cover it

• It’s easier to *downplay* problems if you have some sort of explanation to *put them under*

• Even if the reasoning *doesn’t make sense*, the problems have to get *much bigger* to be seen
The elephant in the support group

• You won’t be the only one out there with a partial diagnosis or the wrong label

• Some support groups are full of elephants asking “Do any other tree trunks have tusks?” and others saying, “Yes, lots of us do!”

• Actual ‘tree trunks’ looking for help with ‘wood fungus’ might become frustrated and confused

• But, if they try to suggest you might be misdiagnosed, angry parents tell them - “You are not like my child!”
An elephant by any other name

• You might be stalled with a **partial or co-morbid diagnosis** – dyspraxia, ADHD, OCD, sensory processing

• You might be like me and have a **coincidental medical condition** distract from everything else

• **It might not be medical** at all
  – your parents went through a divorce
  – you’re transgender or gender role non-conforming
  – you changed schools in the middle of the year
  – you’re a ‘gifted and talented’ child

• Adults can *explain away* the elephant in the room
The kitchen sink in the room?

• Or perhaps you or your family keep looking for answers after your first single trait diagnosis

• You go from specialist to specialist, poking your ‘elephant’ through every door you can...

• And eventually...

“I have tree trunkism, boulder syndrome with co-morbid rope, spears disease, serpantitis ...oh and kitchen sink disorder, not otherwise specified”
The elephant under the sink

Accumulating a collection of diagnoses can be a clue that there’s something bigger or more pervasive underlying all of them.

Autistic people who keep ‘collecting labels’ after diagnosis are more likely to have another condition that autism is obscuring.

Conversely, people with other disabilities or chronic illnesses – diagnosed or not – may be more likely to seek adult autism assessment.
The elephant in the pile

And sometimes there’s more than one elephant!
The discussion that accompanies this talk will be in the **OBS Gallery, today at 16:30**

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