



# The Elephant in the Room

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Autscap 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'**



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# *“The elephant in the room”*



Image – Ben Tonge, Leagas Delaney

# *“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”*

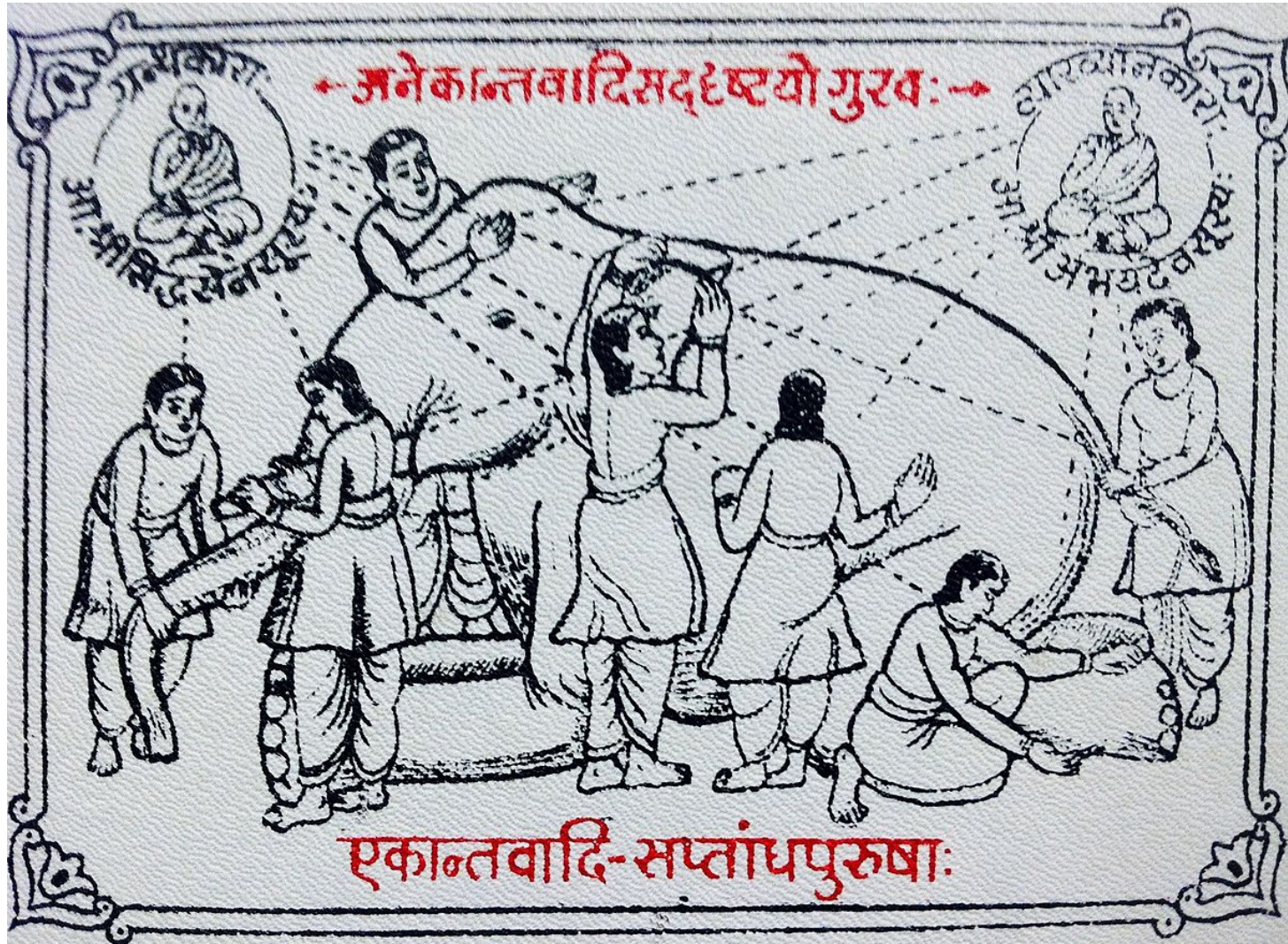
- Before accepting neurodivergence, people in the child’s life might actively look for ways to avoid acknowledging the ‘elephant’
- *“We know she’s a bit different, but that’s just what makes her the unique person she is”*
- *“We don’t want to limit him with a diagnosis”*
- Teacher: *“Autism’s controversial 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





# The Parable of the Elephant

- Dates to at least the 1<sup>st</sup> 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

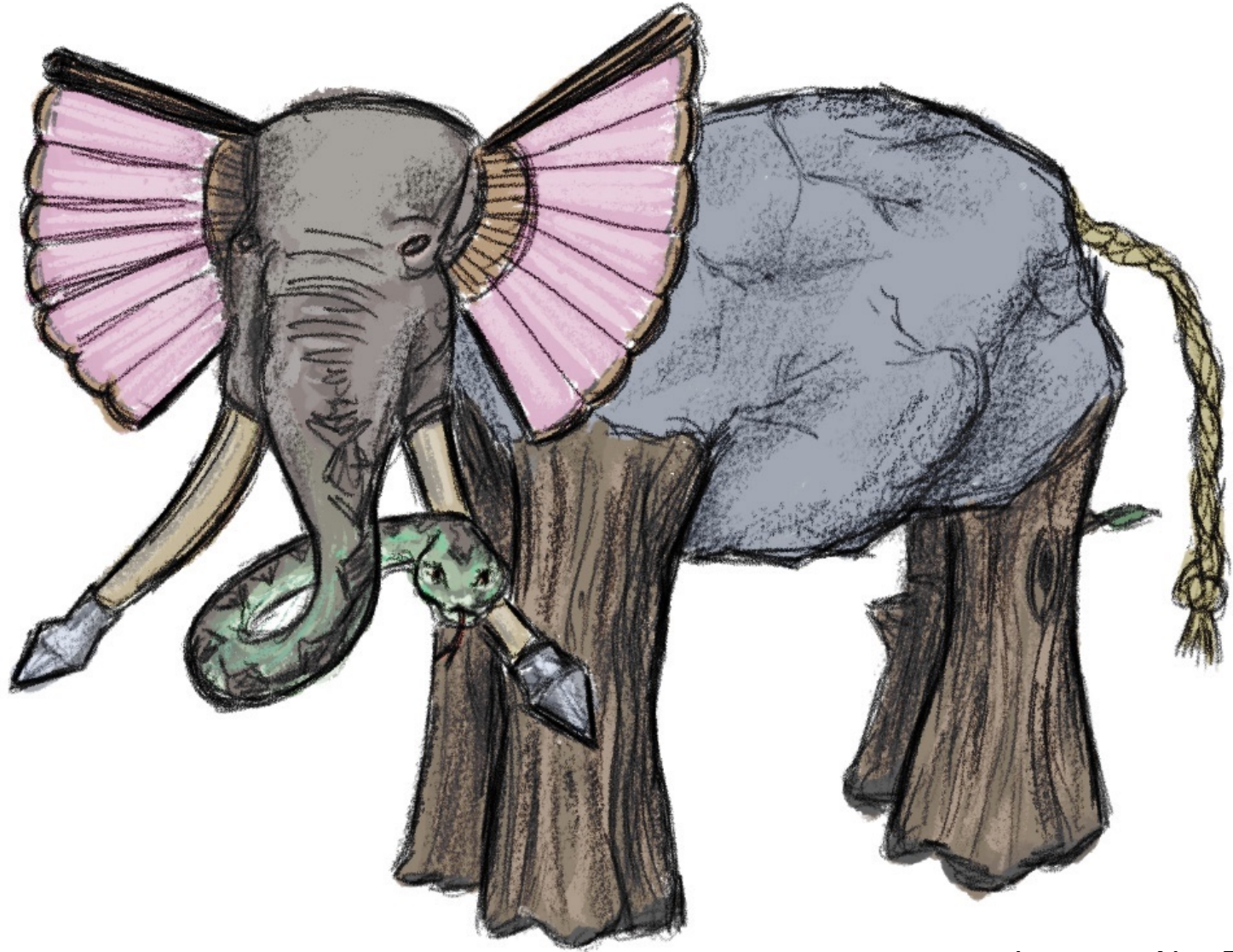
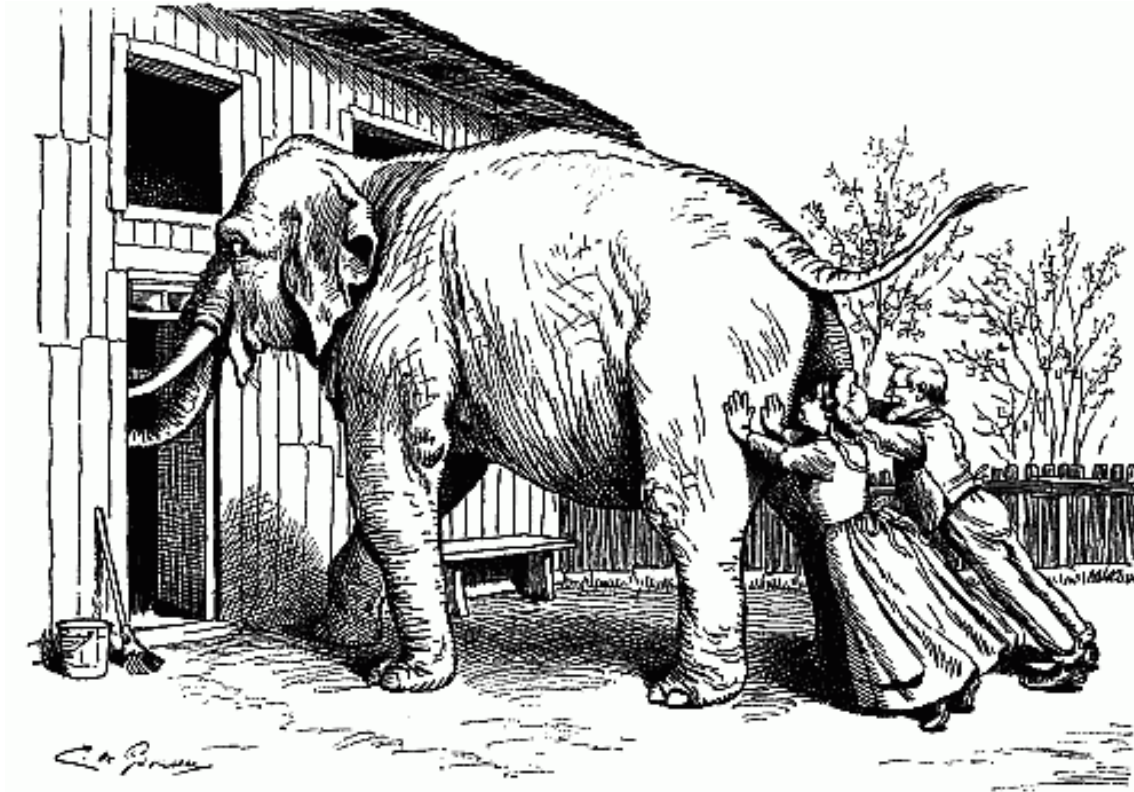


Image – Nat Titman

# 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*

# 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 childish, 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

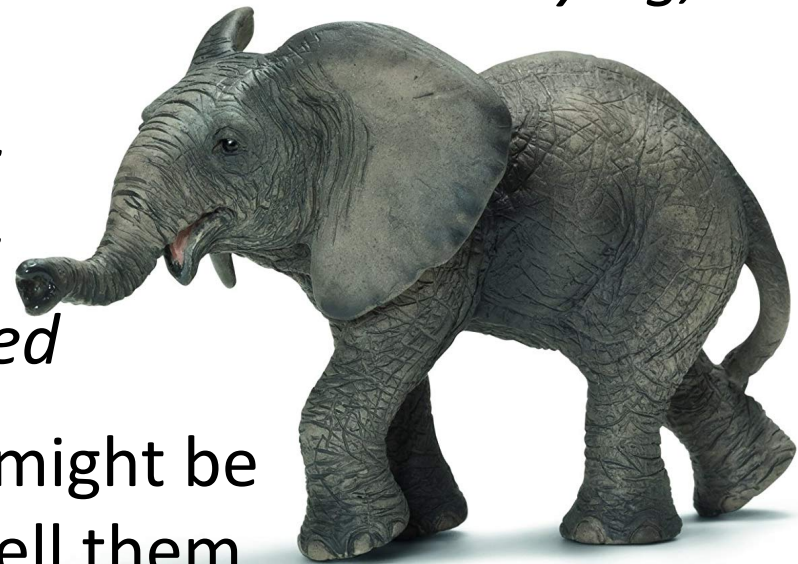


# The elephant under the rug

- 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!"*



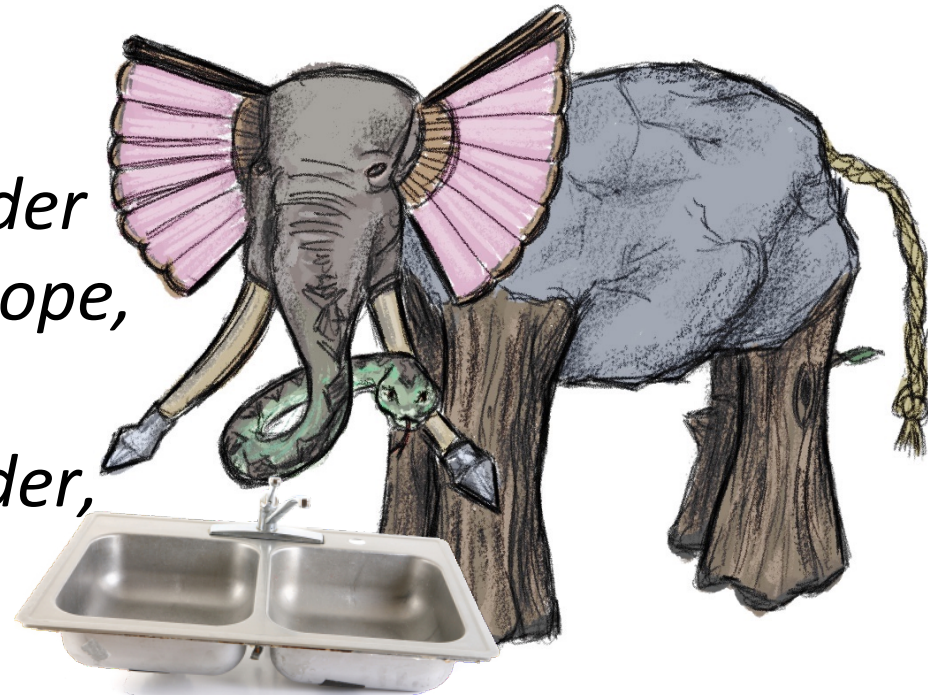
# An elephant by any other name

- 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"*



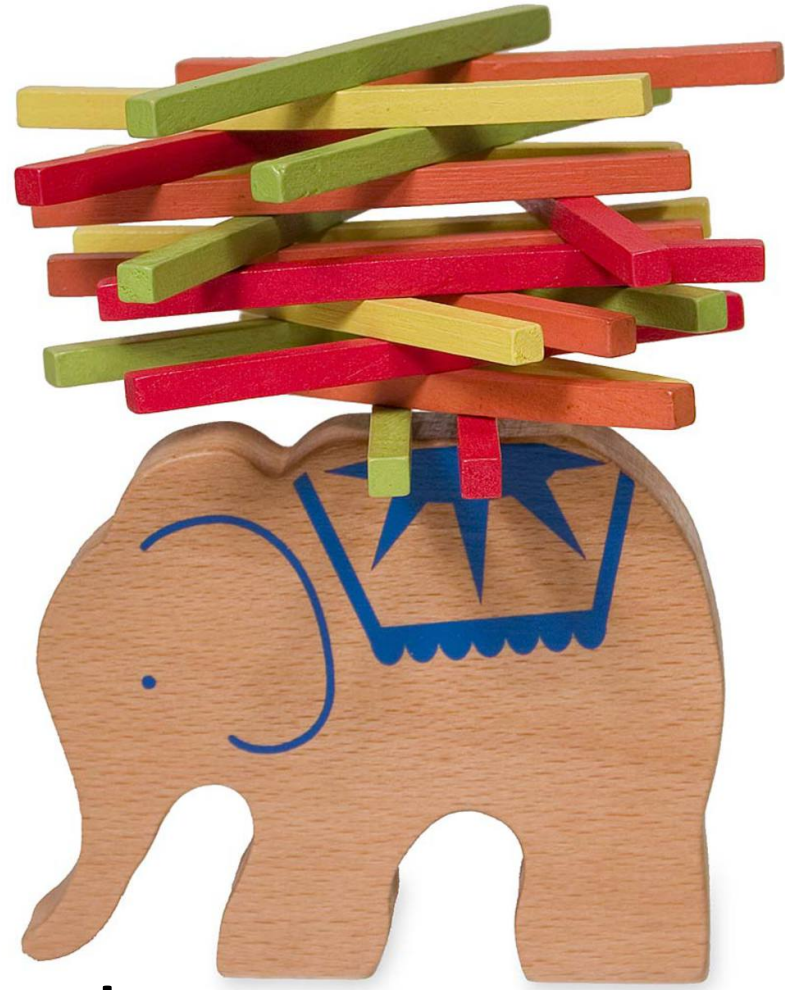


# The elephant under the sink

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**



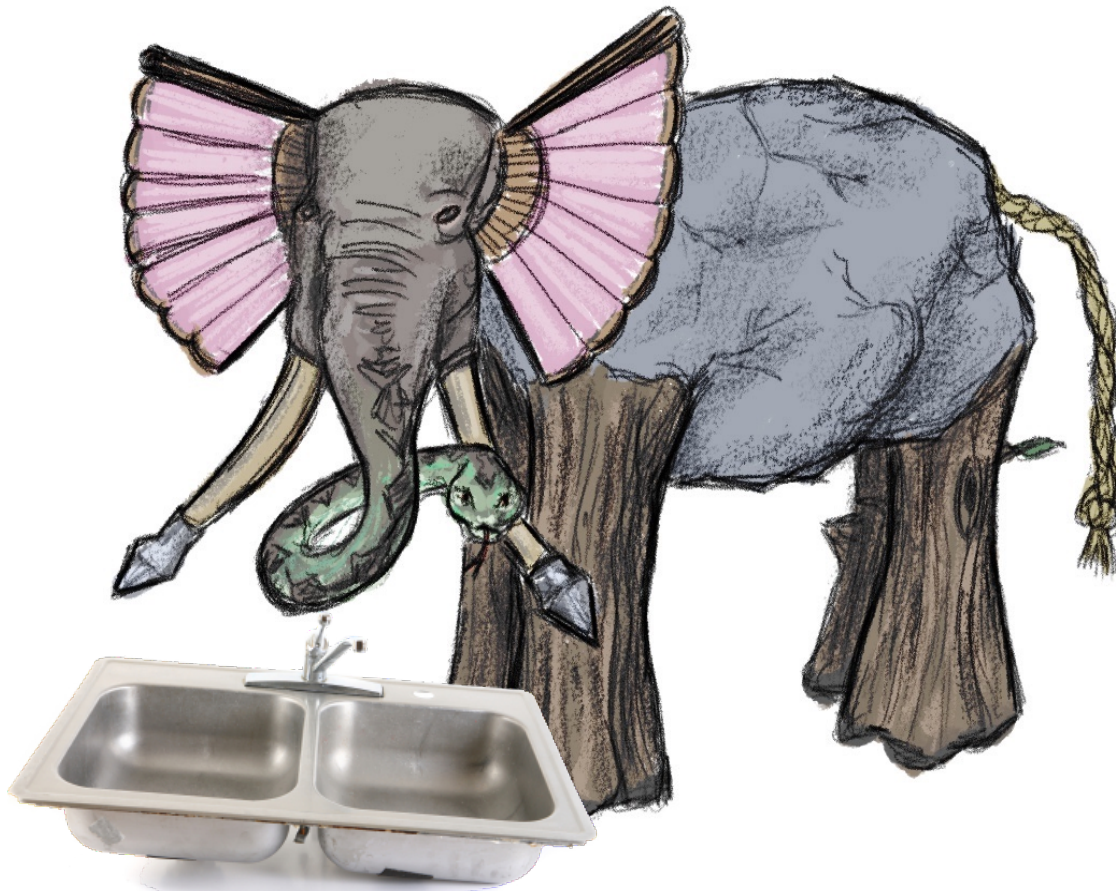
# The elephant in the pile



*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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