Twitter Thread by <u>Ann Memmott PGC</u>■





How many people know they're autistic, so far.

These are the studies from various countries and teams.

England & Scotland data taken from the official school records.

The problem is, not everyone knows they're autistic.

The tests & assessments tend to find white males/

/because that's what they were expecting to find, many decades ago.

It simply never occurred to people that autism might 'look' different in e.g. females, BAME communities, older people, males who don't present in typically male ways, etc./

I suspect we are nowhere near finding most of the females.

Why do I suspect this? From conversation with diagnostic professionals who are updating their info and having 'oh heck!' moments

From parents struggling to get their daughters diagnosed, whereas the son was easy/

/...from the number of autistic females I've encountered over the last decades who had gone 'under the radar' for so many years until someone finally had that 'aha!' moment.

And so many with identical presentations who are still struggling to get diagnosed/

Being clear that many diagnostic teams are fabulous.

It's simply a reality that the tools they were given were designed to pick white men.

Let's look at some examples:/

Do they make 'unusual' eye contact?

This can be cultural. It might be immensely rude to look an adult in the eye, in some cultures.

What about their hobbies? Oh she plays with dolls? Great.

Oh, he plays with toy trains? Autism!

Even though the 50 dolls are lined up/

Are they a female that shows sudden changes in mood/angry anxiety? Personality disorder! MH! Are they a male that shows sudden changes in mood/angry anxiety? Autism!

Repeating, many diagnostic teams are good.../

So many females get to adult years before being considered for diagnosis, dragging behind them a list as long as your arm of Things They Didn't Actually Have But Got Diagnosed With before someone said 'oh...ah...!'

So, when I see prevalence statistics saying it's 4:1 boys/

I am rather suspicious of that number. I really don't think it is.

I think it's far closer.

Colleagues from BAME communities talk of societal and cultural barriers to even thinking about getting a child diagnosed, also/

So...if Scotland has 1 in 40 school pupils who are autistic so far, we can make a good guess that there are more. And my estimates of 1 in 30 aren't too far wrong.

There's no reason why England should be different; England's rate was the same as Scotland in 2010/

We have various charities still claiming it's 1 in 100, based on data from 10 years ago.

It ignores the data from our own Schools statistical teams.

It's really weird to keep using that figure.

When are we going to stop?