Twitter Thread by Shelley Gray ■



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A little thread about language and #HumanRights...

Recently I shared an NHS letter (not mine) that started with the line 'The vast majority of babies are normal.' It meant 'normal' as opposed to babies born with particular conditions, including #DownsSyndrome

Regularly hearing negative language about your child is emotionally wearing. And surprisingly hard to challenge in the moment (for me anyway... which is possibly why I choose to try and challenge it by writing about it).

A fortnight before Rosa was born, a consultant explained the problem they'd spotted with her digestive system, and then went on to say "...and now I have to say something to you that's not very nice... this condition is often associated with Down's syndrome."

In hospital, nearly three weeks after Rosa was born a nurse repeatedly told me what my baby wouldn't do compared to a "normal baby".

In my first conversation with the Health Visitor her opening question was "Did you know she was going to be Downs?"

After Rosa's first multi-disciplinary review we got a letter that started with the heading 'Problems' in bold text.

... and so it goes on.

But it's not just difficult because someone is speaking about your child using language loaded with negative assumptions. It's difficult because you know it's a reflection of how people with learning disabilities are widely viewed and treated.

It's also hard to read stories about people with learning disabilities dying several decades early (https://t.co/11zZxITagN), or being more than three times more likely to die of COVID (https://t.co/EsJ55Ffl3H), or very often experiencing hate crime as part of daily life.

All of these things are further impacted by additional factors like poverty, race etc...

The depressing headlines are the result of discrimination that's built into how we choose to organise society. Words that cast people as 'other' and reinforce an idea that their lives are less valuable help create the conditions in which that's allowed to happen.

Of course, the other part of this story is that language evolves and society progresses. There are words relating to Down's syndrome that I was familiar with as a child, that Rosa might well never hear.

The experience of having a baby with Down's syndrome now is very different to what it was a few short decades ago. And in my experience of navigating life and services with Rosa the negative words are undoubtedly outweighed by the positive ones.

I hope people keep growing more thoughtful about the words they use (often hurtful language isn't meant that way)...and I hope all the warm words about a more equal society post-pandemic really do result in different choices - ones that lead to the realisation of #HumanRights

And I hope that, even once my girl doesn't have her extreme cuteness to fall back on, she'll be just fine ❤■

