

Thank you for asking me to talk to you all today about the sex-based rights of learning disabled girls and women.

Girls and women like my daughter, who I shall call Helen, and Cassie, an autistic, non verbal woman who was raped and infected with HIV in her supported living home, raped by a male carer, or carers, at some point or points between 2007 and 2015. This happened in the London Borough of Brent, and Brent's review paints a dreadful picture of neglect.

Imagine being Cassie? Her mum?

I am so angry. And frightened too. Because my daughter, Helen, who is now 18, has a similar profile: non verbal, profoundly autistic. Who, when she moves out of home, will live with 24/7 care. Who when we die, will only have people paid to be in her life. People who will come and go and will randomly disappear one day to a new job.

For the last three and a half years, my husband and I have been asking our local authority to collect data on the protected characteristic of sex, not just gender. Additionally, we have been asking for a commitment from them to commission same sex services.

We believe:

- Firstly, that Helen, and all those like her, have necessary and intrinsic rights to safeguarding and dignity: her intimate care takes place behind closed doors on a 1:1 , lone working basis and she cannot bear witness
- Secondly, we believe that Helen does not have the mental capacity to choose or 'feel' her gender – the only thing we can fairly and truly ascertain is her biological sex
- And thirdly, we believe that Helen's sex-based rights cannot be honoured unless the sex of all parties involved in her care is known and recorded.

Our local authority does not collect data on the sex of its disabled adults in adult social care.

Their justification for this includes (and these are direct quotes from correspondence):

- *'forcing individuals to disclose their sex assigned at birth would potentially be a violation of their human rights'*
- *'we have no intention to facilitate or support the commissioning of single sex services in the current market'*

Where to start with these? When very senior professionals appear to not know that sex is a protected characteristic? And think that gender is - or that it means the same thing? And appear to have lost sight of why the protected characteristic of 'sex' (and therefore safeguarding and dignity) matters to disabled women, who *we all know* are many times more likely to be abused in care? Who *we all know* are at much higher risk of predation because they have no voice, cannot advocate for themselves, bear witness or fight back?

It is extremely hard to square our local authority's position with the laws that protect Helen's rights as a very disabled young woman.

Once you start seeing the erosion of sex-based rights, the examples pile up.

1. In 2020, Helen's special school changed its same sex intimate care policy, to a cross gender one. This was 'to celebrate staff diversity'. The school eventually conceded and the policy was changed back
2. In 2022, Helen started the process of transferring from children's to adult services. Our discussions were back at square one. So much so, that our new social worker told us with confidence, 'no-one collects data on sex in adult social care any more.'

My husband and I fast realised that the only way forwards was to present as much evidence as we could.

We sent Freedom of Information requests to all 33 adult social care departments in London. All of these FOIs are in the public domain and we have collated these into a summary report.

The results reveal:

- That only 4/33 London local authorities collect data on the sex of their clients in adult social care
 - There were no equality impact assessments undertaken in any London local authority relating to collecting data on gender instead of sex
 - There is a wide range of permitted values in the gender field and these differ across local authorities - from male/female to non binary, demiboy, demigirl, etc
 - Noteworthy individual responses include Bromley, which stated that it can determine someone's gender on the basis of their first name; Havering & also Hillingdon, who answered the question on whether they had a field for sex, by confusing it with sexual orientation.
3. In 2023, our LA told us they would need to assess Helen's mental capacity to test our assertion that it was not possible to ascertain her sense of gender. They told us that the results of this mental capacity assessment would be subject to a best interests meeting.

We resisted this because there really is no reliable way of determining Helen's understanding of *gender*. How would this be done? Asking her to point to a photo of a girl? A boy? What would happen if she misunderstood the question and pointed to a boy? Would this make her trans; non binary? Or quite ...

what?

We resisted this too because her lack of mental capacity has *nothing* to do with the sex-based rights she already has and because we were extremely uncomfortable about the fact that the test would be unique to Helen, in both its content and in the fact it was having to happen.

There is so much more to say. Each example I have just given, and there are more, could be an essay in itself.

Helen and her cohort remain hidden members of society. They start special school at the age of four, the playschemes they attend in the school holidays are disability-specific.

Opportunities for Helen to be included in mainstream settings outside of her family and close family friends are almost non-existent.

But the reality is, we – all of us – do not grow up with Helens, we don't go to school with Helens, Helens all go to other schools, *special* schools, and are taught by other teachers – *special* teachers. *Other* people are seen as being responsible for them.

If any of us are to claim a commitment to balancing rights, this must also include acknowledging the existing rights that Helen, all Helens have, and not just dismissing these, with no consultation or further discussion because they are an inconvenience to a political agenda or ideology.

Having someone perform your intimate care is hard to get used to. No one should ever assume this is any different for Helen or that she has no feelings of modesty. We should remember that she does not have the luxury of ever opting out of care, and above all, we should remember that her dignity and safeguarding only exist as long as the risks that undermine these, are properly understood and recorded.

Every professional working with Helen – her headteacher, her social workers, very senior professionals in Adult Social Care, have let her down.

Helen's protected characteristic of sex remains unrecorded. And given our FOI results, so does Cassie's. How *on earth* has this happened?