Reclaiming the Human in Healthcare Manifesto



Image of the Humanising Healthcare Project logo - a cartoon image of a medical doctor, dressed in a white jacket with a love heart on their lapel.

























The Easy Read in this presentation has been prepared using images from



Who we are



We are a team of self-advocacy based researchers, university researchers, and healthcare researchers.



Researchers try and understand things and find things out. They do this to try and make things better.



Some of us have learning disabilities, some of us are neurodivergent, and some of us are not disabled.



The self-advocates on the team work at Sheffield Voices, Speakup Self Advocacy, Barod, and Sunderland People First. Other researchers on the team work at the University of Sheffield and for the NHS.



We have been working together on a research project called Humanising Healthcare. We have been trying to understand what the good healthcare experiences of people with learning disabilities are.



We are sharing things we find out from the Humanising Healthcare project in lots of different ways to suit different people. This Manifesto is one of the ways we are sharing what we have learnt together.

Key words	Photosymbol	Plain English Word
Reclaiming		Finding something that has been lost.
The human		A person like me or you with rights and ambitions. Ambitions are things that you want to do or things that you want to happen.

Key words	Photosymbol	Plain English Word
Healthcare		The places and people that help us with our health.
Manifesto	Manifesto What we want!	A document that sets out our ambitions – what we think is important and what we want.



We want health and social care workers to read this Manifesto carefully and think about what they can learn from this Manifesto.



We want health and social care workers to make their practice better after reading this Manifesto. You can tell us how you are going to do this on the QR code here or at this website:

https://forms.gle/zVRakgacQ9rZHpXJ8

Reclaiming the Human in Healthcare Manifesto

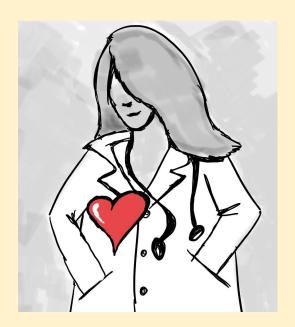


Image of the *Humanising Healthcare* Project logo - a cartoon image of medical doctor, dressed in white jacket with a love heart on their lapel

Photosymbol

We believe and recognise that



People with learning disabilities and autistic people have equal rights to healthcare.



People with learning disabilities and their families are the experts in their own lives.

They know what is best care for them.



People who work in services should be kind and caring. Being kind doesn't take time or money.



People who work in services should put people with learning disabilities at the centre of everything they do.



If you want to do healthcare well, you have to work alongside self-advocacy groups.



People with learning disabilities and autistic people die too young.

So it is really important to improve healthcare.



We must make sure that services are:

- Kind
- Caring, and
- Give the best support possible.



We must share good examples of people being treated well – as equals – and respected.



We know that health action plans, health passports and reasonable adjustments all help – but we need to act upon them.



All of us should treat people right. We should do as we would be done by. Healthcare workers should see the person as a person and not just a patient.



We must respect each other, pay attention, support one another and communicate clearly.



Healthcare workers want to help patients understand what will happen to them in their healthcare.



Healthcare workers should:

- Use plain language
- Be clear
- Explain risks, and
- Explain how the treatment will feel.



Humanising healthcare means seeing the person as a person not a medical label. It means understanding how the person lives and feels outside the healthcare setting.



During Covid, people felt unhappy and upset. People lost lots of things: confidence, self esteem, contact, and interests.



Some people were left out because they did not have a way to use the internet or weren't sure how to use it. Self-advocates helped to show people how connection worked. Digital skills were learnt.



Homes and communities should be safe places.



Humanising Healthcare is an idea about everyone being treated as human beings. It is about learning what good healthcare looks like, and how we can make it better.



Finding out about humanising healthcare means creating shared spaces where researchers from different backgrounds work together.



These different backgrounds include researchers from:

- Self-advocacy organisations
- Universities
- The NHS



We believe in honest research that shares both the good and bad sides of healthcare services.



Any learning disability awareness training and equality training must include people with learning disabilities as leaders.



Put the views of people with learning disabilities at the centre of all healthcare staff training.



Repeating information can be tiring and upsetting; find ways of sharing information between healthcare workers and services.



A society is a large group of people who live together and share things. Our society should be judged by how we treat the most vulnerable.



People with learning disabilities and autistic people are often left out or forgotten because it takes more to include us. Making sure we are part of society makes everyone's lives better.



The fights of people with learning disabilities link with those of Black, disabled, and LGBTQ+ communities. We must work together for truth, fairness, and for the common good.



Many communities have had to fight hard for their human rights and place in society. People with learning disabilities and autistic people share this fight and can learn from other people's struggles.



Healthcare workers need to know that people with learning disabilities are also carers and family members too.



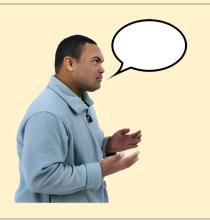
Healthcare workers should use good practice for explaining things to people with learning disabilities when they work with families and carers with learning disabilities.



Our advice is to use easy read, plain English, and pictures. This helps family members and carers with learning disabilities make better choices with the people they care for.



There are times when people with learning disabilities and families face hard healthcare choices.



Sometimes, healthcare workers have to make these decisions. Healthcare workers should do their best to explain why these decisions have to be made.



Thank you for reading this Manifesto.

Further information



Some of the things we share are for university researchers, some are for healthcare workers, and some of the things we share are for people with learning disabilities and their close others.



You can read more about this work here:

https://sites.google.com/sheffield.ac.uk/esrchuma nisinghealthcare/writing-and-dissemination



We also have a place online where we celebrate the incredible work that self-advocates do to help make the healthcare and lives of people with learning disabilities better.

This work is by Barod, Sheffield Voices, Speakup Self-advocacy, and Sunderland People First.



You can learn about some of this work here:

https://sites.google.com/sheffield.ac.uk/esrchuman isinghealthcare/exhibition