

Reclaiming the Human in Healthcare Manifesto

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About the project



We think it is wrong that people with learning disabilities and autistic people experience worse health than other adults. That is why we set up the Humanising Healthcare study.



Humanising Healthcare is an important idea. It is about how the services and people who care for us should treat us.

Our field work



We did research at two NHS services in the UK: an epilepsy service and a learning disability service.



We followed 13 patients with learning disabilities as they went to healthcare appointments across 18 months.

Our field work



We watched and wrote detailed notes about their healthcare appointments and their experiences at the services. This is called an **ethnography**.



We interviewed people with learning disabilities who took part about their lives and their healthcare.

Our field work



We also interviewed people who they told us were important to them.



We asked the people who took part to tell us the story of their lives and healthcare. This is called a **narrative interview**.

Our field work



We found ways of helping people tell their stories in ways that worked for them.



For example, some people in their interviews did:

- Talking Mats interviews with symbols
- Drawings of their ideal healthcare worker
- Cartoon strips of an appointment
- A photo sharing interview

CO-PRODUCTION



Our co-production approach



Our project team included advocacy-based researchers with learning disabilities and/or autistic self-advocates. We met as a co-production group or an executive team every month or two over three years.



The self-advocates were meaningfully involved at every stage of the research project and were members of the study's executive team.

Our co-production approach



The self-advocates on our team are expert researchers, expert analysts, expert theorists, and expert disability activists. “Experts-by-experience” does not even begin to cover the contributions self-advocates make to research.



The Manifesto that Simon and Matthew are about to present was developed as part of our two-day in-person co-production meeting this summer and was led by the self-advocates on the team.

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

PHOTO  **SYMBOLS**[®]

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.



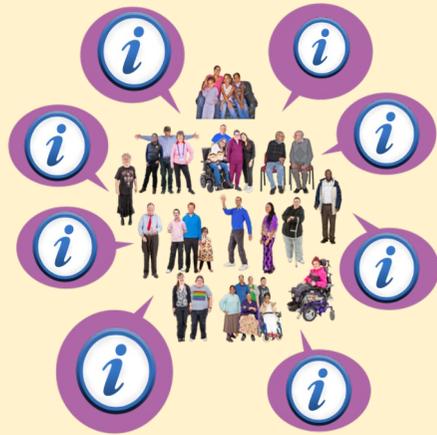
Some of us have learning disabilities, some of us are neurodivergent, and some of us do not have learning disabilities.



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 find good experiences of healthcare.



We are sharing things we find out from the 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.

Here are some key words we will use

Photosymbol

Plain English Words

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. Simon 16

Key words	Photosymbol	Plain English Word
Healthcare		The places and people that help us with our health.
Manifesto		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 - please scan this code on your phones

<https://forms.gle/zVRqkgacQ9rZHpXJ8>

Simon

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 the 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.

People 1st



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



People with learning disabilities and people with autism 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 with respect.



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



We all 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 each other 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 making shared spaces where researchers from different backgrounds work together.



These different backgrounds include researchers from:

- Self-advocacy groups
- 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 community is a large group of people who live together and share things.

Our community should be judged by how we treat the most vulnerable.



People with learning disabilities and people with autism are often left out or forgotten because it takes more to include us.

Making sure we are part of the community - that 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 listening to our 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/esrchumanisinghealthcare/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/esrchumanisinghealthcare/exhibition>