**York Disability Rights Forum UNCRPD event 18th November 2021 via zoom**

The presentation provided was delivered and we played Tara Flood’s Inclusion London launch event video to start.

York Disability Rights Forum recently gathered information on their member’s priorities through a survey [overview included in evidence]. The top three priorities were Physical Accessibility, Health and Social Care and Attitudes and Beliefs. As a result, these were the articles we chose to focus on in this group.

**Article 9 – Accessibility**

The Article was explained to the group and a discussion was opened on how the UK was doing in meeting its obligations under this article.

*Blue Badge exclusion*

In York we have been having a battle with the council about [Blue Badge holder access](https://ydrf.org.uk/about/city-centre-access/) to the city centre for the past 18 months. We cannot access, on an equal basis with others, the physical environment of the city centre. It’s a big issue in York [YHRCN report included in evidence]. The decision whether to make this situation permanent will be made tonight. [This subsequently [was made permanent](https://ydrf.org.uk/2021/11/19/york-permanently-excludes-blue-badge-holders-devastating-lives/) despite passionate pleas from disabled groups and their allies against it; a [fundraiser](https://www.crowdjustice.com/case/closedtous/) has been set up to fund a legal challenge with Chris Fry].

Other physical issues in York – pavement cafes, lack of dropped curbs, lack of ramps to access businesses and services.

Access to information during the pandemic has been a huge problem. Lack of interpreters at the covid briefings, lack of easy read versions of advice and the letters sent out by local council. Information was released significantly later for groups who needed alternative communications.

Public transport – Concerns around transport have changed perspective since the pandemic. One participant described that visually impaired people are more worried about being infected on the bus because people are close to them, rather than worrying if they’re on the right bus going to the right place which was previously the concern. Our local bus service First York have been clear that they will not install audio-visual systems into their buses until they have new buses which they cannot currently afford. Bus stop information also leaves a lot to be desired.

From a mental health, anxiety and working person’s point of view, the public transport system is so unreliable that people struggle to put faith in it. Similarly, trains cause huge travel anxiety, as wheelchair users are getting left on trains. We felt this was linked to stereotypes about disabled people not having work to get to, or having more time so if their time is wasted it doesn’t matter – things that would be unthinkable for non-disabled people. There needs to be some real work around this to make progress.

Example: one participant is a commuting student and needs to be at university at 11am and has to leave her home at 7.30am to get there – 20 mins to the train station, the train may or not be on time, 1.5 hours on the train, then needs to get a bus which is the biggest uncertain factor. They could get a later train to get in at 10:30am but can’t depend on the bus, so must arrive at 9:30am instead. It completely disincentivises doing things in an environmentally sustainable way – they drive into York when they have to be at university at 9.30am as this would not be possible otherwise.

Example: Another participant leaves so much extra time which means travel takes double or triple the time that it does for non-disabled people. They had an experience of needing help to get on and off a train to the airport. The lift in York was broken but they were not told or supported until they asked for assistance. They finally managed to get onto the train. At the other end they were thankfully getting off at the end of the line. Nobody came to get them off the train, they couldn’t raise any alarm and it was only when the cleaners came to the carriage that they were able to get off the train. Even after allowing for these things to happen, they still nearly missed their flight on that occasion. It is very disempowering and incredibly stressful if they are using public transport alone. If they have a carer or friend with them, they can jump off the train to get help, but if they are on their own, they can’t do that, so they have no power in this instance.

**Article 25 – Health**

The Article was explained to the group and a discussion was opened on how the UK was doing in meeting its obligations under this article.

Experience of being a disabled person in hospital – not being given the same care as non-disabled people. They were not treated equally, but also, things that would have helped, like having carers in before visiting hours, was not allowed. Carer hours did not fit around visiting hours so the only time they could leave the ward was when a friend (who was able to push a wheelchair) could take them out.

They had a history of an eating disorder and even though this was unrelated to the issue they were in hospital for, this history really skewed they way they were treated. They were seen as a ‘pain’ and made to feel like a ‘pain’. They don’t believe that would have been the case if they didn’t have that history.

Certain diagnoses and histories impact on how people have been treated, or been refused treatment in York.

Example: being a woman and also being young has had a significant impact on how seriously they have been treated by doctors, even female doctors. Before an endometriosis diagnosis, they had a 6 month period, bleeding non-stop for 6 months, but it was difficult to get a medical professional to take that seriously. There’s so much sexism in medicine and its obvious to someone with a condition related with women – there’s a lot of not taking pain seriously and also not acknowledging the impact of having intermittent pain can have and at different times there might be need for different levels of treatment.

Pain is not understood as disabling – whatever kind of pain it is.

One person was talking to their doctor about birth control, they were in their wheelchair and asking about birth control, and the doctor asked why they would need it (implying they would not be having sex). They also have vaginismus and it took years for a doctor to ask them if it was a problem for them that they would like to do something about.

Medical gaslighting was identified as a real problem – changing the tone of ‘why are you experiencing this’ to ‘you are not experiencing this’ because things can be very difficult to diagnose. The dismissal of people’s lived experience of their own bodies is a big problem. Difficult to communicate pain – the pain scale does not work. A lot of disbelieving of people.

Example: The doctor said ‘you probably do have endometriosis but there’s no point in trying to get a diagnosis as it would be invasive so let’s treat the symptoms’. It’s a big cause of health anxiety as there is a worry that the symptoms are being dismissed and not investigated and so there might be something very wrong underneath. Dismissed because they were young, growing, seen as ‘whining’ about pain. Lots of concerns around pain relief, but not about birth control which has so many risks.

Example: In terms of staying healthy, blind and partially sighted people might like to attend a gym. However, when they seek to do this, they find gyms are not accessible, they can’t operate the machines on their own, there are no clear paths between machines, and they have at times been told flatly that they cannot access the gym unless they have a carer with them and sometimes that they can’t come at all.

One last thought on health - growing up in a rural area, the notion that healthcare should be accessible everywhere is absolutely laughable. Austerity has completely decimated healthcare around here: two hospitals closed, one A&E closed.

**Article 8 – Awareness-Raising**

There was a real change in tone around 2010 when the government changed. We started to get a lot of rhetoric around disabled people as benefit scroungers, as people who are committing fraud, and who are a burden on the system. By building that kind of image of what disabled people are like, the government was then able, in turn, to do things like cut benefits or change benefits systems because they basically presented us as either a burden, or as a liar, and therefore, we didn't need the benefits that we were asking for, which goes right against ‘promoting awareness of capabilities and contributions of disabled people’.

Some of the ableism disabled people experience comes from people who love them, the stereotypes are so pervasive in society. Internalised ableism is so destructive because disabled people have internalised the messages around disability. This creates a huge amount of shame around disability which is incredibly psychologically damaging. It takes a lot of work to unpick those messages, especially around embracing a disabled identity or applying for benefits for fear of disbelief or accusation of fraud. People then leave things too late and things deteriorate significantly before they get help.

Example: The presumption of ‘you’re faking this’ was so pervasive that it took so long for them to overcome this and ask for help. They became disabled while at work and wore splints, started using a wheelchair…and each time they noticed they were being taken less seriously as previously or equal to people on the same level as them at work. They were a good manager but were not being given the same platform within the workplace as a result of their disability.

The issue of ‘simulating’ disability – putting on a blindfold, earphones, spending time using a wheelchair. This has a counterintuitive impact – thinking it will create empathy, but it instead creating pity, which is the opposite of the intended outcome. These experiments generate a very superficial understanding of disability and non-disabled people apply all of their internalised ableism to thinking that if they were in that position, they would not be able to live their lives in the same way. Going further is the idea that it would be ‘better to be dead than disabled’, which is still so pervasive. It's people saying, ‘I don't know how you cope’ or ‘how you manage to live and be happy’ to disabled people. People express outright to disabled people that they would take their lives if they were disabled.

It is so important while fighting for disability rights that we spend time highlighting disability joy – we need to have that to balance pointing out the things that need to change with pointing out that disabled lives are happy, are enriched, that disabled people have families, friends and joy. Important also to highlight the relationship disabled people can have with their carers and have this as a positive, rather than a negative. Perhaps the idea of Disability Pride could be centred in disability rights spaces too.

Attitudes changed around disabled people during the pandemic – suddenly being seen as people who can be 'sacrificed', who can be made to stay inside so that non-disabled people could get on with their lives. Pitching their right to not wear a mask or get a vaccine against our right to life, especially in care work was a particular low.

To finish up we watched Svetlana Kotova’s video from the launch event and discussed ways to get more involved.

We completed the evaluation forms and ended the event. [\*FYI: the survey was incredibly difficult for one blind participant to complete as a result of the embedded videos. I completed the survey for her while she spoke to me over the phone instead.]