#Queer #Crip Club – meeting 10.11.2021

Things are definitely worse now. Social care is a big example of this – not only that but now the same problems extend to Continuing Healthcare (CHC) funding.

If you have hidden impairments it is especially difficult because then the professionals never believe you.

Support packages you get given are so limited they are impossible to set up, it’s impossible to employ people.

A lot of agencies won’t take on epilepsy.

There is a lot of fighting over limited resources whether through social care packages or benefits.

Not enough people are informed enough about their rights. Local Disabled People’s Organisations that used to provide this service have all closed or have too little capacity. So many Law Centres have also closed now. In those organisations that still survive the ones doing the work have more and more to do and are more and more up against it. There aren’t enough people to do the work.

Blue Badge issue – to get a renewal I needed a hospital letter dated within the last year. Not know where to go for advice about the procedure. Peer support through Queer Crip Club was the most helpful.

Hospitals and healthcare – so many appointments being cancelled.

“God help anyone who doesn’t know their rights.”

Clear culture shift – with Blue Badges but also Disabled Students’ Allowance – reticence to give you anything.

Examples of students who had packages before being denied on reapplication, and personal costs being chased up.

Issue of reducing carbon emissions and measures to do that being adopted without thinking about impact on disabled people, eg “whole swathes of London where you can’t stop a black cab”; eg heat pumps need houses that are properly insulated and so many disabled people can’t afford this; traffic calming measures adopted with no consultation or thought to safety of disabled people or equality impact assessment.

Local government – used to be more representative and better engagement.

Pre-existing inequalities exacerbated by the pandemic.

Barriers to healthcare – much more pronounced under Covid.

Intersectionality – lack of important pandemic information available in different language, left to charities and grassroots communities – for example family members trying to translate; the more oppressions you experience, the more overlooked you are and the more excluded you are from any policy-making considerations.

Invisible caring – disabled people having to jump through hoops just to access the most basic healthcare but also having to support other disabled people who do not know or are not able to speak up for their rights even though we have limited energy or experiences of trauma ourselves – is so overwhelming – “rapidly worse over the past year”

It is a constant fight to get what you need ever though you are entitled to it.

Can only see it getting worse.

Covid – decisions on who would get care dependent on how overwhelmed the NHS is. – Disabled people are absolutely not important. We are “expendable”.

Not being on CEV list – suggestion that you are malingering if you shielded while you weren’t on it.

Example of only receiving notification to shield a couple of weeks before shielding officially ended.

Experiences of the pandemic varied in some regards – non-disabled people got more of an insight into what it is like to not have access to all these things they take for granted – means you can have the conversation now about disabled people whose access to those things is always restricted/under threat.

But access improvements and adjustments gained during the pandemic now being taken away – need to get message across that you need to be doing all of these things all of the time. Access provisions at universities already been taken away. Students allowed to live abroad and participate remotely but same not permitted for disabled students for disability-related reasons.

Disability services at universities “on their knees” – no where for disabled students to turn for support.

“It feels like people hate you more than they did before.”

After-care treatment in hospitals not happening.

Discharging from hospitals a lot quicker.

Example of being about to give back a CHC package because too many problems to be worth keeping and because so poorly managed by them.

“Every review if a chance to gate-keep and cut services back.”

With CHC funding, too few on it to be able to share ideas and peer support.

“Spending your whole time trying to get your basic needs met makes you ill-er.”

Excuse of pandemic not to do anything.

Southbank Centre – held up as an example of progress in environmental accessibility – actually they cut the parking spaces back; the electronic doors don’t work; there is a Changing Places toilet but the other accessible toilets aren’t big enough for wheelchairs; “the physicality is a bloody nightmare.”

Mental health waiting times have got a lot worse.

Day centres being closed.

Mental Health Transformations – potential for greater recognition of right to a “dignified life”

Excess deaths and pandemic – negative attitudes within the medical profession have become a lot more entrenched. – view of disabled people as expendable.

Social care – “such horror stories”

Brexit – much more difficult employing Personal Assistants and pressure people into having to use agencies.

Lack of social housing. Disabled young people having to live in care homes for the elderly because no accessible accommodation.

“Idea of people having an independent, dignified life seems to have gone out the window.”

Need for joined up care with follow up after hospital discharge.

Appalling that disabled people have to pay for letters to confirm our medical conditions.

“Subject: access request”

IAPT – do not provide letters for benefits

Funding for independent advocacy cut.

Employers are more frugal now – everything is about money even for needs that were not a problem before to meet.

**There needs to be co-production and consultation.**