East Anglia event – 19.11.2021 – 7 – 8.30pm

Notes from 7.36pm

Access to information – acute issue. Local Council – putting outsourced call services in as gatekeepers; services that used to provide advice

“I contacted social services for a review and it took them four months to get back to me.”

“I think it’s a direct tactic – you drive down the needs when people don’t know what their rights are. I think it’s got worse over the past five years

“I think it’s intentional over ignorance.”

“Since being a County Councillor and assuming they want to go the right thing and then finding out the worst, I am convinced it’s a tactic they do use. If they can’t find it, they won’t ask for it.”

Friend – Council housing, Council support – lost vision. Now everything is online staff are refusing to call or leave Voice Notes. Someone from the Council could call but they won’t. Information is on line but she has only recently lost her sight and can’t get support to learn how to access information online. “It’s really nasty.”

Universal Credit online – social services online – sometimes they don’t offer alternatives.

Then sometimes there are only paper options and nothing online.

Huge pockets of poverty and rural deprivation where tech doesn’t exist.

People still assume accessibility is bricks and mortar.

I know someone in Bedford and they are the carer for their brother and they have been in a flat that is not only inaccessible but also bad for them and there is no way to get anyone to listen that they have rights.

The only way to get anything from the Council is to follow the three stages of the complaints procedure and then it goes to the Ombudsman and they will confirm it is discrimination and then the Council will do what needs doing, but unless you go through that procedure, they won’t consider it.

Lack of BSL information about the pandemic. It has to be said. There was no need for that – people were telling them from Day One. And it was only when we were starting to unlock that we got it on one single briefing.

Not just BSL – also need subtitling and access to speech to text.

Right to life – people being restrained, deaths by neglect

Supported housing where there isn’t enough staff to support people to live safely and well. I know someone whose son died who had Down’s Syndrome. He had to take laxatives on a regular basis and avoid certain foods due to his intestinal problem and that poor man died with 25lbs of faeces in his intestinal tract because it ended up rupturing and that was because there was no one making sure he took his medication on time. They didn’t want him to live in a care home setting so he was in supported housing and he enjoyed the freedom but should also have been getting the support.

Where was the right to life for people in care homes during Covid – and what is life?

Intersectional elements – Black Asian and Minority Ethnic communities ending up in criminal justice system because they haven’t had the support they needed at the right time.

Looking at mental health, we have had this whole farce over the Mental Health Act review and the lack of consultation. “It is peddling back badly.”

DNACPRs – substitute decision-making – even for people like Baroness

Care home in our area that had blanket DNACPRs placed on all residents – largely autistic people – for absolutely no clinical reason. See: https://www.hsj.co.uk/coronavirus/learning-disabilities-patients-told-they-may-be-too-frail-for-mechanical-ventilation-if-they-get-covid-19/7027318.article

Schools for disabled people. I’m a teacher and I have reduced my hours. Multi issues. School in Cambridge hired me because I’m autistic. When I needed the accommodations they bullied me out. How the children in that school were treated. The non-speaking kids were dragged around and restrained – tiny Year Fours being pinned down by massive security guards. I did do whistle-blowing for that but I heard nothing about. State schools I think are better in my experience for disabled young people because at least they are around other young people who will advocate them if they need to. Whereas where young people are imprisoned In State schools it’s pupils without support who are targeted for exclusion. It’s got a lot worse over the past five years and I have taught in a lot of schools in east Anglia. There is a lack of accessibility but then if a pupil is seen as needing extra accommodations or needing more work then management starts to target them. There is a complete misunderstanding of what being autistic is. I have seen them not allowed noise cancelling headphones or baseball caps for light and they are expected to act as perfectly neurotypical and if they can’t they are labelled as problems. I have seen this hundreds of times. Support has been cut so many times there is literally nothing for them. There are no school counsellors or anymore and the kids have no one to speak to at all.

Pupil Referral Units – one in East Anglia that had young people from all over coming to it – didn’t even realise when kids were autistic.

Excluded pupils and involvement in criminal behaviour.

“I'd rather type this than say it because it's upsetting and about suicide which not everyone is ok to hear about. … My brother who is also disabled died by suicide this summer because he couldn't speak to the crisis team, they discharged him before he died and didn't follow up soon enough. Mental health and isolation in the pandemic for disabled people has not been taken seriously enough especially for people who have no coping mechanism independently.”

Disability hate crime – treated differently from other hate crimes.

Much more difficult to get someone to represent us due to doing away with legal aid, but also making it look like we are worth less than other groups of people who experience hate crime.

Furlough made it easier to get rid of disabled staff who were struggling due to lack of reasonable adjustments.

The cat was let out of the bag that everybody could successfully work from home but when things go back to “normal” - employers wanting to get us back into workplaces to control us.

Everything the government does is about getting people into employment – never consider those who for whatever reason cannot

House of Lords Liaison Committee - July 2021 - report on failure of government to implement protections / reasonable adjustments in our Equality Act 2010 domestic legislation.

Pressure from local Councils to go into care homes. Example of a woman who due to PAs getting COVID, having to reply on neighbours to support her and then as a result local authority tried to pressure her to go into a care home. “She knew if she went in, she would never come out.”

Friend has had repeated attempts to massively cut her care budget – has happened I believe three times over the past seven years. I want to get on the record this is absolutely due to austerity. The Local Council just doesn’t have the budget anymore so they are repeatedly going back to the same people, going through the horror they are not going to get the support they need to stay in their own homes, so three times within a small number of years having to face the horror that they are trying to get her out and force her into a home. She has a care budget and was choosing to use carers that are most expensive than the recommended hourly amount from the Council, she found cheaper agencies were not providing a good enough service so she chose to go to a more expensive carers on fewer hours and the local authority used that as an excuse to cut her budget to that smaller number of hours but on the same rate as the cheaper local authority and has to find the difference from her own pocket. She is on a zero hours contract as a lecturer so really doesn’t have this money. She can’t spend as much money on food ..etc as a result.

Anything positive? When everyone had to work at home, disabled people were leading because we are very good at finding solutions to problems. Work being able to be done online and people not being dragged to places commuting for short meetings and even on-disabled people are seeing that having to go into the office for a short meeting is a waste of time. So I’m hoping this is a gain we can keep – it won’t be for disability reasons but maybe something we can benefit from!

Recognition that we need to build up on infrastructure for broadband and help people out of digital poverty.

Many people in data and tech poverty.

During the pandemic most disabled children had no access to digital provision – families reliant on a single phone owned by Mum and having to share between all children for accessing education.

During pandemic only small percentage of children from wealthier homes did homework – none of the disabled children did.

Local Council scheme giving access to laptops was kept very quiet! No one knew about it.

Mutual Aid groups – takeaway positive. People still helping each other eg picking up prescriptions..etc. Helped integrate disabled people within our communities.

East Anglia - disabled children from Gypsy, Roma, Traveller communities – most deprived. Data and tech poverty and isolation. Cambridge has a lot of hidden inequality. I have been quite disgusted about lack of understanding about why during the pandemic travelling communities have needed to be in Cambridge if they have family members at Addenbrookes – some of the scapegoating against disabled people may have been ameliorated through the pandemic and Mutual Aid groups but none of that has been passed on to GRT communities.

I accidentally got discharged form my specialist so I have had to get onto the waiting list to get back to the clinic I was at. When I speak to the GP he just says “well, it’s the pandemic” – GP is having to monitor my medication but he doesn’t have the expertise. Issue that doesn’t just affect disabled people but has more of an impact on us.

Clinics have just been shut so waiting lists haven’t bee

I have been pleased that doctors have moved to phone and video appointments – inaccessible for some – but has been beneficial for me so I don’t have to commute all the way to the hospital and the staff seem keen to keep it as well. This could be a real positive if it is made more accessible for those that need.

Mutual Aid – again real positive.