



A Parent Carers Story

PACC Blog - Chasing our Tails

Covid19 present us with constant challenges; the worry about the risk to our and our loved one's health, coping with lockdown, repeated changes to our plans and what will we do during the summer holidays? Even with light at the end of the tunnel and the roll out of the vaccine, it continues to test us with worries about who will get the vaccine and when.

Ensuring that we all have access to the vaccine in a timely and appropriate way is a huge task, and the first thing to say is that there has been a tremendous effort by all involved to do this. NHS and Local Authority staff have done an amazing job in setting up vaccination centres and organising appointments to happen in a safe way. There has however been a lot of confusion in the disability community about how our families will fit into the vaccination programme and the initial guidance provided has shown that those making the decisions don't always have a full understanding of our lives.

Initially unpaid carers were not included in the priority groups at all, so there was a successful campaign by a number of national organisations such as Carers UK and Contact to address this and unpaid carers are now in Priority 6. Even this isn't without its issues since it leaves us in the strange position that paid carers of our children and young people are getting the vaccine now, yet family carers may have to wait for several weeks before they will be able to automatically get vaccinated. All of which seems non-sensical because we all know that unpaid carers prop up the health and social care systems and if we are not well enough to do our 'job' then the system would be overwhelmed.

More recently concerns have come to the fore around those with learning disabilities. Reports have highlighted that individuals with learning disabilities are at much greater risk of dying due to Covid19, than the general population, [you can read more about that here.](#)

This is because those with a learning disability face a range of social, economic and health inequalities, which increase their vulnerability and place them at greater risk of ill health. Currently only those individuals who are identified as having severe or profound learning disabilities are identified as a priority group for vaccination, but the evidence shows that the risk from Covid19 has a much wider impact on the learning-disabled community than just this group. And then there is the issue about how we identify just those with severe or profound learning disabilities? The GP learning disability register doesn't capture all those with a learning disability, at best only half of the 1.5 million individuals with a learning disability in the UK are registered and it is more likely to be a much lower percentage for the younger age groups. In Shropshire we know that very few 16 – 25-year-olds are on their GP's learning disability register, so even if the guidance does change to include all those with a learning disability in Priority 6, how do we ensure that they all get the vaccine? You can read more about this issue and what is happening locally with the vaccine roll out [on the PACC website.](#)

There has been lots of learning from this pandemic, but perhaps the most important thing from our perspective is that it has shown us once again how important co-production is. Working in partnership with people with a lived experience, is the only way to gain a true understanding of how to deliver effective services and interventions. National guidance is all very good, but if it doesn't reflect the realities of the lives of people it is meant to help, then we are just wasting time and resources and will end up doing nothing more than chasing our tails.

Sarah and Zara

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