

Written evidence submitted by a member of the public (CVD0032)

Pre-Covid-19.

Factors that would impact on my ability to cope during Covid-19:

My application for one to one support from the [local authority] Independent Learning Service (ILS) took over a year to be sorted and to reach a conclusion. The conclusion was that I would be transitioned from ILS to Personal Assistant Support (PAS) as it was a more flexible support that would work well with my needs. I had an appointment booked for Friday 13th of March to meet with support services and to sign documents for the transition to PAS could take place.

February –

Increasing and alarming media coverage of Covid-19 in UK and my uncertainty with my support being continued:

There seemed to be total confusion with no idea what was happening. There was not enough information about the disruption because of covid-19 and how that would impact on me as a vulnerable person. During this time, I was still able to meet with my autistic friends and discuss the extremes in response to the support they were getting which was very different to mine. They both are employed and said that the approach of their employers was business as usual and that their support services were taking a day by day approach. Whilst, there were rumours that services were going to adapt within new contingency plans that would prioritise vulnerable service users such as myself, I had no confirmation to that affect. I had no communication or help offered constructively in regards to my current and ongoing support during this time.

The Impact on Mental on My Health:

The combination of increasing fear, confusion and panic on a global and local level and the uncertainty of what would happen with my support transitioning sent my anxiety soaring. Nothing now seemed stable and the volatility and erratic response to the pandemic was impacting on my mental health and wellbeing. To ameliorate my anxiety levels, I focused on trying to contact support services to get a resolution to my situation. The response I received was that they were dealing with a greater situation than mine and that the Council's efforts and energy was in rolling out their covid-19 emergency plans. Understandably, it was a stressful time. However, as a vulnerable adult, I could not get past my personal situation as it was important for my physical and psychological wellbeing that I would be supported come what may. In addition, my meeting with support services to complete the transition by signing the forms was cancelled two hours before the meeting was due to take place and 4 days before Covid-19 emergency plans was ramped up. This caused me to melt-down with severe mental distress and anxiety attacks and a complete feeling of being out of control of myself, my situation and how was the disruption going to hinder me getting the support I was desperately needing. My support worker at the time was due to speak to me but failed to

respond and had been taken from me as a support worker and put onto something else and with no one that had been replaced to support me. I was completely alone, with no advisor, no support worker, no sign-posting or offers of support. All I had in any concrete communication was 2 weeks prior to this, which, I believe was false assurance that the transition would be completed and if there was any delay I would continue to receive ILS and I wouldn't be left without support.

I tried every way I could, given that I am autistic and struggle with planning, organising and resolution, to get the situation resolved. The static situation and ruminative thoughts just sent my mental health on a downward spiral. Day by day, my hope was diminishing and I knew that even if I tried to keep some normality to my routine, I might stabilise my anxiety. I could not just sit there, despite my reducing ability to cope. The news that the managing and supply and demand put on supermarkets was causing extreme reactions e.g. customer vigilantism against other shoppers. This terrified me and I was afraid I would be abused or attacked. So, as part of my holding onto routine, I would walk 2 miles to the nearest supermarket in the earliest or latest time to avoid any perceived threat to me. I would then walk back the 2 miles.

However, I found this incredibly exhausting physically and mentally and day by day I retreated further into staying at home, not exercising, not caring for my personal health and hygiene and importantly not eating because there were hardly any provisions in my fridge or food cupboards.

I felt completely lost and helpless. Desperate to reach out to someone or importantly, that someone cared enough about me that they would reach out to me.

March – Emergency and Panic by Government and the realisation I had slipped through the support service cracks:

The places where I would normally get food e.g. local takeaway, convenient stores started to become affected. Coupled with my worsening mental health day by day, the ability to feed myself or have deliveries of takeaways was now diminishing. In addition, I have a genetic liver condition that requires me to have specific dietary needs and supplies, which ordinarily the shop keepers and customer service who knew me would ensure they had in stock. Combined with my autistic sensory challenges the food I usually would eat was chosen because of taste and texture which I struggle with and growing demand on supply and the disruption to provisions and people's panic buying, I could not gain any access to the provisions I normally would eat. Importantly, fresh produce e.g. vegetables, meat and fruit.

Overnight, takeaways that would deliver to me closed without any warning, the disruption to food supplies and empty shelves and the gradual cessation of transport services beat me down. I felt a futility to any of my efforts to help myself. I was out of fight and decided to permanently stay at home.

Mid- March- (20th - 23rd) Lockdown

Worsening Mental Health:

By the 20th March I realised I was going to run out of Diazepam tablets which was prescribed for anxiety. It is not a repeat prescription drug. It must be reissued once the GP had spoken with me. I rang the surgery and was told that there were no GPs to help me with this and that they couldn't reissue the tablets at the time. However, the receptionist on the phone did say that I should only contact them again if it was emergency. Emergency! This was an emergency, with the pandemic causing mass fear and no supportive help and my inability to look after myself. There was no greater emergency!

This lack of humanity and kindness caused me to melt-down again. I had followed every procedure and request set out for me by the authorities and sectors that would ensure I would be cared for. I was failed by support services, and now my GP surgery.

I felt I was a 3rd class person that didn't even register on the bottom of the pile by those who were supposed to help and support me. I felt worthless, unloved, undervalued.

Suicidal Thoughts:

I started to think that there was no point in me living. No one cared. I was forgotten. I started to rationalise that I was dead either way; by contracting and dying from Covid-19 or by ending my own life.

April – small rays of light at the end of the tunnel:

Good outcome: The Surgery finally organised and delivered my meds.

5th April: I put out a cry for help with food supplies on Social Media and a connection from my past collaborations in research and autism advocacy saw my online post and contacted me.

The person in question contacted my local Assembly Member who organised for community voluntary services to get provisions for me on a weekly basis. That person was a Community Volunteer. Somebody different called me from [the Assembly Member's] office asking if I needed further help. Somebody reached out to me and that gave me a contact to the outside world. I asked for help with the ILS situation and offered to assist in the community if needed.

Simultaneously, without any warning, an employee acting on behalf of [the local council] also called me and asked if I needed food. I was inundated by various calls that I just said yes

and lost track of what I had already had planned for food provisions with [my Assembly Member's] office. The Council scheme did not accommodate my dietary requirements; everything was rushed with unwanted food substitutions. I tried to pay the person. However, they said that I will be billed at the end of the lockdown. This sent my anxiety levels soaring as I was afraid that the length of time and the amount I potentially owed would be more than I could afford and importantly had not mentioned this in the phone call to me prior to the food deliveries. I decided there and then not to access that service.

On a practical level, having [a Community Volunteer] delivering provisions that include your dietary needs lessened the stress of worrying about how was I going to feed myself.

During this time, several talking services contacted me all at once and I was overwhelmed and overloaded by the sheer volume of different calls that required mental energy and physical ability to talk at length. This unfortunately, impacted on my stress levels causing cognitive fog and extreme tiredness. I couldn't continue to engage with these services all at once.

Time and me in space have been completely distorted and I'm finding that being in lockdown extremely disorientating. My fatigue levels have increased, I'm more susceptible to cognitive fog and cannot move in thought from anything but the present.

April 20th: Currently, I am communicating with one talking service most days of the week - a local scheme to connect with vulnerable people in the community. I have built up a rapport with [a volunteer from the local scheme] and this has meant I feel less isolated. He contacts me to confirm whether I need to talk. However, as I am autistic I am challenged by knowing when I need help. My understanding of my own needs and my own perspective is affected similarly to understanding others' perspectives.

The uncertainty of what is going to happen next with the whole pandemic situation and lockdown and further disruption and the fear of contracting covid-19 once lockdown is phased out. The idea of what symptoms and how it operates and the inconsistencies went beyond my scientific comprehension because those claiming to be from the scientific community to mainstream media via the Government and then to us, as a scientist myself, I knew that what was being reported in these methods did not follow the established fundamentals of virology. This increased my fear and distrust and scepticism that the Government's management of the whole situation was completely mishandled. Knowingly, running behind what most of society logically would have expected e.g. targeted isolation, testing, contact tracing. Governments were given a warning that a respiratory virus of a pandemic level would be highly likely, given, that animal viruses have transferred to humans in the recent past e.g. swine flu, bird flu. I believe that the UK Government has neglected to learn from other countries particularly, South Korea. The spontaneous conflicting information that I and society have been bombarded with is damaging not only to mental health and wellbeing but society. Their duty of care to me and society is just window dressing as their actions are contrary to that.

UK Government have been distracted by other items instead of focusing all the efforts into the real crisis in testing, PPE and contact tracing and deliberately avoiding any offers by other political parties and communities to join forces to discuss preparation after lockdown.

In conclusion, I fear for myself, my community and country now and in the future. The repeated inability for the Government to take responsibility for their actions during Covid-19 and previous mishandling e.g. austerity, flooding of villages and homes and Brexit and welfare reforms has meant that I do not trust them to look after my welfare and the population. Personally, I am terrified that as an autistic person who is bewildered and confused about this whole situation, would be considered a threat to others in the community, potentially attacked by local community vigilantes or apprehended by the police and other authorities simply because the Governments lack of preparation, precise information and constantly renege on guidelines when I am only following what they tell me to do.

I fear for my life in the current Government and associated authorities' hands.

Since there has been no proactive engagement so far, like the government is following a blind strategy that has no scientific or virology basis, along with focusing on issues that would seem irrelevant, I do not trust what they say or what they claim to be doing.

I also do not trust due to the number of reported deaths in mainly confined spaces that 'lockdown' was a good idea at all - There are still questions on the origins of this virus as well as the need to still hold officials to account: which the removal of such along with other powers that are not required (and with no proof of their requirement having been expressed) should be an utmost priority.

I feel that with better decontamination procedures, that this will provide the best model, without having to stop unduly people's freedom of movement within the country.

There also needs to be a memorandum on the proper use of technologies when it comes to diagnosis, reporting & linking up. Whilst it may seem far-fetched, it is alarming that there is a focus on a 'quick fix' vaccine that once again does not prevent contagion, and in addition seems to be being pushed by private interests, rather than on the recommendations of totally independent scientific basis, especially that without reliable data (most data, has been rushed with no confirmation of those cases that the virus was indeed cause of illness and death, being made on a very broad and conflicting range of symptoms that have the potential to mask other issues) cannot go ahead without being subjected to the same sensible timeframe as any other inoculations, along with civil protections so as to assess adverse reactions to avoid preventable harms. There needs to be a focus on proper antivirals and remedy medications first, so as to allow any inoculations to be thoroughly tested, and all the contents of such, need to be made public without any hiding of 'additional ingredients'.

Whilst initially I dismissed the idea - I now need to say, the focus on the roll-out of 5G (both terrestrial 'cell' sites & the Space X satellites) during an emergency, when all efforts should be in maintaining our present communications network that whilst not perfect does provide

an adequate service, is also puzzling - whilst I don't want to jump to conclusions, I believe this and the tracking app & bluetooth wristband technology will be misused, whether that be by violation of privacy & unlawful tracking of people that is specifically prohibited by Data Protection & GDPR regulations, along with questionable safety measures that make us feel like guinea pigs at a period of time which is not only highly insensitive, but does not give anymore reassurances that the government are focused on 'doing the right thing'. The use & implementation of the technology needs to be completely rolled-back until such times as proper investigations can take place.

Such ceasing of other areas & implementing full investigations when we are in a position after the crisis to deal with it, also equally apply. For example, have heard mention of a 'World Reserve Currency' being implemented in places without any public announcement, despite apparently a report mentioning that in a test that it did not work. Another example, is the continuing policies for further austerity that would practically bring everything further to a halt (in my opinion, it's 'national suicide' to keep going with these, when it is very clear that without giving investment to the public's 'wallets', that there will be no 'recovery') - we cannot compete on the 'world stage' if we are making our people poorer and less able to deal with things, along with dictating what they can and can't do that violate our fundamental rights, and has denied healthcare.

What needs to be done, is proactive discussions with all communities that can be implemented - along with a restoration of all fundamental rights & freedoms immediately, and to never allow such a use of extraordinary powers of breaches in personal freedoms to be implemented ever again.

Recently, the rule for not going more than 5 miles in Wales, has been a nightmare, as this prevents me from visiting facilities that I need to keep me going and to receive support I cannot get in the local area (in fact the nearest is 3 times that distance - and whilst being told 'do not use public transport', also means that I have been disabled and disadvantaged compared to others who have support from local family/friends).

I have felt throughout this whole this like I was being treated like a child rather than as a knowledgeable and reasonable adult that has been penalised despite doing nothing wrong. It has got so bad that it has made me more determined to petition to get these rights back for myself and all people in the realms of Wales & England.

I have found it difficult to fill this in and to answer questions specifically, given the changing scope of the situation. I would welcome and request as part of my needs to be able to be interviewed if a more summarised answer is required of your questions, which whilst I understand the limitations at this time, I do not have the appropriate support and am fearful of my voice being silenced by discrimination if I went further afield for this help. Please

anonymise any information that might compromise my data protection and do provide me a copy of the final version.

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