



HOUSES OF PARLIAMENT

Joint Committee on Human Rights

Corrected oral evidence: [The Government's response to Covid-19: human rights implications to long lockdown, HC 1004](#)

Wednesday 13 January 2021

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Members present: Ms Harriet Harman (Chair); Lord Brabazon of Tara; Ms Karen Buck; Joanna Cherry; Lord Dubs; Baroness Ludford; Dean Russell; Lord Singh of Wimbledon.

Questions 1-20

Witnesses

[I](#): John, husband of a care home resident; Helen Wildbore, Director, Relatives and Residents Association.

[II](#): Alison, mother of young person detained in an assessment and treatment unit; Matt Clifton, Chief Executive, bemix; Alexis Quinn, Rightful Lives.

[III](#): Sarah Burrows, Founder and Director, Children Heard and Seen.

Examination of witnesses

Alison, Matt Clifton and Alexis Quinn.

Chair: We now move to Alison and Alexis and to looking at young people in mental health detention who are autistic and/or who have learning disabilities.

Q8 **Baroness Ludford:** Alison, previously when we took evidence from families of young people who are autistic or have learning disabilities, or who were detained in mental health hospitals, we heard that at the early stages of the pandemic they were unable to visit their loved ones, in breach of their right to family life. Your daughter is currently detained. Are you able to visit her now? If not, why not? If you unable to visit, what reasons have you been given?

Alison: Our daughter E has a neurodevelopmental problem in that her birth mum drank alcohol in pregnancy. She has foetal alcohol spectrum disorder. Over 7,000 babies are born every year with this preventable disability.

There is no provision for her in the UK anywhere, yet there are more children and adults with foetal alcohol spectrum disorder than with autism. We have three siblings with this. For all her life, we have had to battle for the right provision and services, so us not being able to see her is an extension of the 20 years of arguing and fighting for these children's rights.

E became poorly as a child 18 months ago, and she is highly traumatised by not having the services. I will not go into the details, but it was the lack of services, provision and professional awareness of her disability that caused her to have a breakdown. Already, lack of human rights have impacted this young girl, who was a beautiful model and doing really well but who has become a person who was sectioned with all her rights restrained. She is now a violent, angry, very sick young woman.

We are not allowed to visit her. She has been in hospital or care systems since 1 October and our visiting has been extremely spasmodic. We were in level 2 and suddenly went into level 4, and all contact stopped. There was nothing. All we had was a 10-minute phone call. Her disability is that she needs to see people, because she is a visual learner. Trying to hear us on the phone was further traumatising her in an environment that did not understand her disability, did not have her needs met and was making her more traumatised.

She could not understand why her mum and dad, who had always been there for her as her external brain for 18 years, were suddenly not available to her and that strangers were dictating what happened in her life. When she could not fathom why she

Oral evidence: The Government's response to Covid-19: human rights implications to long lockdown

could not see us and was further traumatised, she was held down forcibly and injected in her bottom to quieten her. You can imagine the pain of that young woman, who was in her prime, and of her family, who are distraught. We are not allowed to visit her. I have even asked for a window visit. That is excluded.

She has fewer rights than a prisoner. She is stuck in a place and has the emotional age of an infant. If she were on a children's ward, I would be allowed to visit her, but because she is just 18—she turned 18 in hospital at that time—we are denied all contact, because she is an adult. Yet last year her receptive age was assessed as 2.11 years. That girl needs her mum and her dad. She went in with trauma, and she is further traumatised and in such a state that I do not know if we will ever get her back. She is seriously ill.

I was going to play you a minute of a recording I took, but it is so distressing that I cannot play it, out of respect for her. She was screaming, "Mummy, I need you, I want you. Mummy, where are you? Do you love me?" I gather you have that to listen to later. It is not for the public.

Yesterday, she made a comment, and I would like to read to you what she said because I feel we should be giving her a voice. She is 18 and she is excluded from what she wants to say. I called for a review CTR, because her needs are not being met and she is no better after being in an assessment unit for seven weeks. She said to me, "Let me read from the back of my CTR stuff. My name is E. I'm in hospital, poorly with mental health. Coronavirus has made my mental health worse. I'm really bad. Some days I just want to take my life. Please help me. I feel like I can't cope anymore". She was screaming at me when saying this. She said, "My body feels weird today. The sad thing is I miss my mummy and daddy", her brother and her pets. She gave the names. She said, "I miss Mummy's cuddles". This is so traumatic for a young child not to be able to access her mother and her carer's love.

She had such separation anxiety before she went to hospital that when my husband and I went away we had to return, because she was so distressed about us being away. She has been failed so much in her life that we are the only ones, in her view, who can stand up for her rights and understand her.

You can imagine that this Covid is absolutely shocking. The things that she has said about what has gone on—I was not there—are hearsay, so I am not prepared to say publicly, but you have a transcript of what she has been saying. If you can imagine, as a parent listening to that it is agony. Every day we just cry because our child is incarcerated and she is not helped. The public are

crying out for help for these young people. There are no services. Now Covid will not even let me advocate for her. She does not have an advocate. Social workers and police are allowed to go in there, but a mother and a father, who have been by her side 24 hours a day, are not even allowed to look at her through a window. This is inhumane. It is cruel and it is not right.

I have asked and asked. I had to have a bit of a temper tantrum eventually. We have half an hour a week only to hear what has happened to our child. We are not allowed any documentation, nothing. She is deemed to be aged 18, so we are not allowed, yet we are her nearest relatives. The meetings are taken up by everyone else having their say, so we do not get enough feedback.

I told them that she was a visual learner and that she needed to see us, so we now have Zoom, but I have seen staff taking the iPad from her because she wants to talk to me and she is crying and she has gone over the 10 minutes of allocated time, so they forcibly take it off her. This is not right. This is a child who then has an injection in her bottom, and they should never inject anyone unless all areas are seen first to be carried out.

She has massive sensory integration needs. It is her footings of a building, if you like. In seven weeks, not one thing has been looked at, nothing, so none of the structure in her life has been given to her. I have sent in her sensory integration equipment and it has been locked away. Staff have told her, "You can't have it. You're too old for toys". They are not toys. They are her wheelchair with her regulation. Would anyone take a wheelchair away from someone? No, they would not.

Not only is she not having her needs met, but the only people who understand her are being prevented from being with her. Her mental health is so bad. She is so poorly and it is making the rest of us so ill from watching it. It is just cruel.

Chair: Thank you for explaining that. It is absolutely heart-rending, Alison. You are helping us to look at the overall picture by giving us an example of how it affects your daughter as an individual and you as a family. Although our job is not necessarily to take up individual cases, if you want we will work with you after this committee session to talk and to approach the care home to see whether we can help with the hospital. We will liaise with you to see whether we can help on an individual basis.

Alison: Yes, please.

Q9 **Dean Russell:** Alison, thank you so much for sharing what must be incredibly painful testimony with us all. It is very moving.

I know that you explained just now, but for the purpose of our reports and so on, what have been the main impacts on you and your daughter of not being able to visit for such a long period of time, please?

Alison: The impact is that this young girl still believes in Father Christmas, yet she did not have a Santa sack. She was stuck on a ward where they did not celebrate Christmas and did not recognise it, but she knew.

It is so painful to have it so clinical. She was failed in the first place by going in there, and is failed further by being in there and the only people who have ever stood up for her are prevented from going in. We should be able to go in there. Perhaps we could if we were given the jab so that we were not carrying the virus. I am shielding, so I am safer than most people going in and out of that ward anyway. I am less of a danger to them than they are to me, but I am prepared to put my health at risk for my daughter.

Could you ask the question again? I want to make sure I have answered that, please.

Dean Russell: Of course, I am keen to make sure that we have a clear outline of the tangible impacts of not being able to visit over the past year. I know you gave some earlier, which were difficult for you. It is so that we can get a clear idea of what things need to be looked at.

Alison: My daughter, for all her life, was basically obsessed with me. That is part of her condition. She could not be without me. I have worked on that for a long time to try to make her more dependent, but she still wants to get into bed for cuddles, and if she is distressed she lies along the bed with me. You can imagine that, suddenly going into a place that is so alien without her huge need met, there was going to be massive distress. Her already traumatic distress has been exacerbated beyond belief.

She is now hysterical. She screamed on the phone to me just before I came on here, "I hate you. I'm going to kill you. You've abandoned me here". This is a girl who adores me, but her mental state has caused her to turn on me, because I cannot make her better. It is painful. Our contact now is about 10 minutes and it is distressing. She cannot even be civil to us anymore. She just screams. Her swear words are something else. This is a girl who was quiet, sweet and lovely, and then suddenly—I do not like to use the word "monster"—she is alien. She is just so poorly.

We cannot see her. We cannot make it better. By us not having that contact, she feels we have abandoned her. She is already

adopted. For that to happen and by the only people who have ever stood by her is wicked.

Q10 **Baroness Ludford:** Alison, thank you so much for giving us this evidence. It is clear just how distressing it is, understandably.

We had understood that the government guidance to providers of services was that they must allow families to visit unless an individual risk assessment had been made. I am not sure if anything has changed under the current lockdown, but that is what I understood.

Have you had the opportunity to put that to them and get a clear answer as to the legal basis for refusing you physical visits? Have they said that it is to do with Covid testing and vaccinations? If so, have they offered any solution to that?

Alison: Nothing, no. I ask every week. I put it in emails. I am probably a nightmare mother, because I do not take no for an answer. I have badgered them and have tried to get them to understand her disability and her needs and that she needs us to visit. I get, "No". This was before the national lockdown. This was when her care home went from tier 2 to tier 4. We have not seen her for over five weeks.

Even the Government say that you can go out for exercise, so why can she not even walk outside with somebody else and have us walk past and stand two metres away? There has to be some compromise or some innovative way. She might want to cuddle me, and that needs to be managed, but it is cruel. It is just, "No, we're in lockdown". There is no discussion. It is, "No".

Dean Russell: Alison, the description you have given sounds so painful. Have they given a good, logical, written reason why they are not allowing you to do this? You said that they say, "No".

Alison: They have not given us a reason for why we cannot visit, why they are not treating her properly or why she is no better. We are excluded and that is it. I did have to have a little bit of a temper tantrum and threaten all sorts to be able to FaceTime her. That is only once a day. The other day, she was talking to a professional on FaceTime and overlapped our time, so by the time I got to speak to her the time was nearly over. The staff took it away and she was hysterical, because we had only just started speaking.

There does not seem to be any understanding that this is a child in a woman's body who has rights. She is under section, so they can do what they like. If she does not comply, they just inject her. It is out of the Dark Ages. It is awful.

Dean Russell: Finally, have you escalated this further within the system? Where else has this been raised?

Alison: Yes, I have raised it through complaints. I have raised it to the service manager. They got fed up with me, because I was constantly at them for her rights. Then, within 24 hours, they were going to move her to a place where it was nearly all pinning down and injections. It was totally inappropriate. We are a bit wary, because if we say anything they can legitimately remove me as her nearest relative and can take control. There is no response. It is just, "Sorry, we're in lockdown". It does not matter what I say. All the complaints I have registered have come back completely twisted and out of context. It is awful. It is barbaric. It is wrong.

Dean Russell: Thank you for sharing that.

Alison: Thank you for trying to help.

Q11 **Dean Russell:** Alexis, thank you for joining us. On this panel we have heard many testimonies. If it is okay to mention this, you have first-hand experience of being detained in an assessment and treatment unit. I was keen to understand what you think the impact would have been on you if you had been denied visits from friends and family, please.

Alexis Quinn: Admission is traumatic. It usually comes after years of abuse and a real build-up of trauma, stigma and isolation. I was in hospital for three and a half years, sometimes hundreds of miles away from home.

Visitation is such a huge part of connection and recovery, especially if, like me, you have been detained for a long time. Visitation is often the only link, as Alison said, to the outside world. However, even if you have been in hospital for a short time, the effects of not seeing family and friends can be enormous. It can literally be the difference between having the will to live and wanting to give up. It can be the straw that breaks the camel's back, so to speak.

For me, visitation formed part of my weekly routine. I liked to see my mother and daughter every day at visiting time. Without that, I would have missed my daughter growing up. More importantly, my family provided that stability, which is missing from ward environments. Most units are able to accommodate this daily visitation, but with Covid I cannot imagine what people are going through. For me, I felt happier when I saw my family and it was like I mattered. The visits structured my day. They were the only thing I looked forward to. They provided me with something to live for.

From a practical perspective, which is important, I relied on my mother to bring me food that I preferred. Autistic people and people with neurodevelopmental conditions, like E, might have unique diets that are not accommodated in hospitals. When my mother was not able to come—I had three months when I was denied visits in hospital—it peaked because it was not accommodated.

I am autistic, and when routine is broken it creates a dysregulation and a real inner turmoil. My whole sensory system is on fire. My skin is burning. My eyes are burning. My ears are burning. That kind of dysregulation is often a direct result of the ward environment and having your routine broken. This results in restrictive practices, restraint, seclusion and forced medication, which adds to the trauma.

When I was in hospital, visitation was the only contact I had with the outside world. Once I did not have visitors for three months, I was cut off from my community. It is so isolating and so lonely and has an even greater negative impact on your mental health. Over those three months, because I was separated people became such a source of anxiety. I can imagine this is happening with Covid. You get adapted to your new insular and disconnected normal. Being locked inside and not allowed to see visitors, you have to then relearn how to interact and pluck up the courage to see people when you are allowed to again. That happened to me in just three months.

On a personal note, in one hospital I was worried for my own safety. When my mum and dad were not in sight, the culture of interactions changed and staff were more punitive and did not accommodate requests as freely. For example, my mum and dad would always ask what I had done and expect to see me. When they did not come for those 12 weeks, I did not even get to go outside in the garden to get some fresh air. Activities were restricted and so on.

Ultimately, seeing your family is normal. This is another reminder that these restrictions mean that we are not normal and we are not quite human. It is not something we should have to beg for, even in a pandemic.

Dean Russell: Would the measures such as one-day visits, iPad time to see family and so on during the lockdown period have made a difference to you? I appreciate that perhaps physical visits might not have been possible. Would those other measures at least have some relief?

Alexis Quinn: Yes, of course they make a difference, but it is nothing compared to seeing your family. It is a scrap. Some people cannot use devices or they struggle to communicate. I am autistic. When I was in hospital, for periods of time I was mute and certainly was not communicating in the way I am communicating with you now. It is not sufficient and it is not a reasonable adjustment, and it will not meet everybody's needs. It will not meet the needs of most people who have neurodevelopmental conditions.

Q12 **Dean Russell:** Thank you so much for sharing that. Those are important points that you have made there.

Matt, I welcomed the announcement earlier today in the Chamber of the House of Commons on the White Paper for the new Mental Health Act. I understand that you have been involved in a campaign group called Right2Home, which campaigns to get young people discharged from hospitals and returned to live in the community.

I am interested to know your experiences, and those of the families you are in touch with, of being able to visit their loved ones.

Matt Clifton: Thank you for the privilege of representing families today. For this session, we were in touch with 26 families over Christmas and during the last eight days of national lockdown. Their stories echo what Alison and Alexis have already shared. It is not a large sample, but in its common themes it is a clear indicator of the desperate plight of families across the UK.

To share some extracts, a couple stated, "We're no longer allowed to visit our son due to the lockdown. It is devastating for us and traumatic for him". We saw a desperate message from a detained young woman saying, "I want to go home with my mum for Christmas. Please help me. I am upset today. Please, please help me".

One mother was able to visit her teenage daughter for one hour a week, but if visitors missed the timeslot the visit was disallowed. This mother had the crushing experience of travelling 150 miles to see her daughter and arriving 45 minutes late because of traffic, which meant that access was denied. Her daughter, in her own words, said, "I feel violated. I feel broken and I cannot see my family. I also feel confused and worried about what might happen next. I just want to see my family". Her autism means that she struggles to talk using Skype on the hospital's one shared computer. That hospital has now imposed a complete blanket ban on visits during lockdown, as have many others.

A mother told us that she last saw her son on 30 December for a one-hour visit, wearing PPE outside in the freezing cold. In her son's own words, "I'm a hostage in this hospital". A father told us he and his family would visit anytime and anywhere allowed, but visits are blocked and promises to resume access have been broken.

We were told of a teenage boy whose home visits every three weeks have been blocked by lockdown, leaving him, in the words of his parents, in extreme emotional pain and increasingly violent. The whole family is badly affected, including his nine year-old sister, who is confused and scared by what is happening to her brother.

A young man messages his parents again and again, "I miss you and my brothers. Are you coming to get me out so we can have a fun time?"

I realise the Committee has focused on young people, but I must include this brief account from a couple who had travelled every week for 19 years the 240-mile round trip to see their son. He is in a private sector secure setting rated "inadequate" by the CQC last year. Visiting was stopped in the first lockdown. Raised hopes of visiting were dashed by later high tiers and lockdowns. This couple has not seen their son in 10 months. They say, "We are heartbroken. He begs us to come and cries on the phone. He doesn't understand at all and he thinks we've left him".

There are several common themes in the stories shared with us. First, parents understand that settings are under severe pressures and have to act responsibly to protect everyone from the risk of infection, but parents have witnessed their children go through multiple traumas of the kind Alison described. No wonder a parent reasons, "Given the profound immeasurable damage done to my child, when a mental health setting has had 10 months now of experience to be Covid-secure and lockdown-ready, when I am ready to be tested, to wear PPE and to do everything necessary to be safe, how can a blanket ban on visiting possibly be justified and necessary?" That is why these restrictions are breaking down trust with families.

Secondly, we hear the words "I feel powerless" again and again. You have heard a strong parent today in Alison, as you did in the last evidence session. Many are strong. They rightly call themselves "warrior parents", but some we talk to are just worn down and broken by the ordeal. It is rare not to hear the words, "I feel powerless", stuck at home, wanting desperately to do something, waiting for an update from professionals, holding on to that short precious chance to make contact with their child.

Thirdly, parents feel deeply devalued. They know that paid carers are in contact with their loved one, often agency staff with no relationship of trust because regular staff are sick or are self-isolating, and their reasoning is simple: "If caring can be made safe for paid carers, why can it not be made safe for me when I am being meticulous with safety, because seeing my child matters more than anything, and I have unique, deep knowledge of my child and bring vital care that no paid carer can ever come close to replacing?"

As Joanna raised in the previous panel, parity between paid carers and unpaid family carers should be obvious. It has been successfully argued recently in the course of protection but it should not come to that. We would emphatically endorse what Joanna said earlier about the potential for legislation to support essentially family carers.

I have one final thought. There is a danger that good measures such as video calls and the prospect of vaccination become a reason not to move heaven and earth to enable family visits in person. As Alexis said, being there in person is critical to families right now. We cannot get to a point later in the year when we are vaccinating fellow citizens who are utterly broken.

On behalf of the families who kindly shared with us, I thank the committee for giving a voice to their hidden anguish today.

Dean Russell: Thank you, and sorry to interrupt you just now. Please thank all the families who fed in to give us that testimony. It was helpful for the committee. Thank you so much for sharing those insights. To you, Alexis and Alison, thank you for spending that time with me.

Q13 Lord Singh of Wimbledon: My question is to Matt and Alison. In our reports on these issues, this committee has repeatedly made the point that priority must be given to bringing an end to the inappropriate and harmful detention of young people. When we heard from family members in May last year, they told us that the pandemic had meant that discharge planning for their children had been delayed. Is this still a problem?

Matt Clifton: Discharge has improved through measures such as online care and treatment reviews. I know of hard and difficult work, local to us in Kent and Medway, being done to keep discharges on track despite the barriers of the pandemic. Recent high tiers and the national lockdown are definitely major setbacks. Discharge is a delicate process, because it means huge upheaval and change yet again for a person, even though it is what they want.

For sustained success, it is essential that a new team of carers from the community gets to meet the person face to face and establish new relationships of trust. That is vital for success. That must mean going into the setting. It cannot be done just using video calls. We have reports of community teams being prevented from going into settings because of lockdown. That is deeply troubling and, in our view, cannot be justified except in the event of an outbreak in a setting.

Lord Singh of Wimbledon: They are appropriate comments, and I do hope that they will be taken on board. Alison may wish to come in, if she would like to, to describe her daughter's current situation and the problems she is experiencing trying to get effective treatment for her.

Alison: There is not one place in the whole of the UK that can specialise in foetal alcohol spectrum disorder and query mental health. There is nowhere. The only place, or our best bet, would be an ASB unit for learning difficulties, so that is where she is now, but it does not specialise and—I have to be quite blunt here—they are not listening. I have written books on her disability. I have trained doctors, teachers and social workers. I have been in this field for 20 years. They say, "Yes, I'm listening", and they do nothing.

With her prospects, yes, it would be good to put her in the community, but at the moment she is so dysregulated and ill that she probably needs a specialist residential setting to get her to a level where she will be safe in the community. Where she is now is not going to be a long-term thing. We looked at a place only today that is 235 miles away. That is the only place in this country that might be able to meet her needs.

It is crazy. Seven thousand people a year born with this. There is no provision. There is poor provision for people who are autistic. If you have foetal alcohol spectrum disorder, there is nothing. The NICE guidelines are not even coming in until the summer, so there is nothing. Nobody understands. There is no education about it. These young people are left in prisons or mental institutions and stay there for their lives, and yet these people are innocent young people who deserve to be treated for their disabilities.

Lord Singh of Wimbledon: Your heartfelt comments have a lot in them. I do hope that in our report these things will be taken on board. Thank you so much.

Chair: Thank you, Alison, for talking to us about the urgent situation in relation to your daughter. We take on board what that says about the general situation and will work with you to see

whether we can help in her individual circumstance.

Alison: Could I say one thing more? My daughter has not eaten for seven weeks since she has been in that unit. She is at a dangerous body mass index. The hospital does not understand her disability and they are giving her medication for binge eating, which prevents her eating. She is a bag of bones. There is no understanding of her needs. I appreciate that they are trying, but there is nowhere for these young people. It is urgent. I cannot visit and bring food that she might eat. All I have been doing is going online all the time—it costs a fortune—to have it delivered to her.

Q14 **Chair:** We are left, because of your testimony, in no doubt about the urgency of the situation.

Thank you, Alexis, for being so articulate in explaining the practical reality and how much it means. Thank you very much indeed for explaining that so clearly.

I thank Matt, too, for his testimony. Could you thank all those families who gave their stories to you? We know they are only tiny snapshots, but each one of those was heartfelt and heartrending.

All the testimony from the three of you is a spur to action for us as a committee, and I hope the Government will listen to it with absolute seriousness. At this actual moment, the Government want to prioritise this issue. This is not about next year's legislation. This is about the absolute here and now. It is the urgency of the situation that you have made absolutely clear. We thank you for your testimony and will take this forward.