

# Scottish autism

WHERE AUTISTIC PEOPLE  
ARE VALUED

## **Q&A Session with Professor Jason Leitch, National Clinical Director, Scottish Government 7 May 2020 at 7pm**

### Question

We've had a lot of people worried about schools and a lot of autistic children struggling with the school closure and making that transition. Parents are worried about when that will be lifted and what the transition period will be. What notice will be given before schools return?

### Answer

That's a good question and an important question particularly for the community that cares about autism whether it's the kids themselves or the parents and the carers and the grannies and grandpas.

The law may not feel like a helpful place to start, but the law is that we've got to review what we're doing every three weeks. The next stage of that is Thursday of 7<sup>th</sup> of May and then the next one will be the end of May. There's no suggestion that we'll suddenly announce on a Thursday let's all go back to work on a Friday. So I am absolutely confident that there will be a lead-in time to whatever we do even if it's very minor changes around some of the elements that we're doing.

There's a specific education review group that the Deputy First Minister is leading with public health advice from the likes of myself and others, but also educational advice from mainstream educators and from interest groups. My wife is an English teacher and teaches additional support needs kids and refugees, so she teaches English as an additional language. There's input from that group and input from those who care about autism so I'm very confident that group will take into account each of those settings.

My instinct is school is going to look a little bit different for a while and I can't draw you what it will look like just know or give you dates on when it will look like that and I think it might come back at different stages. For example, early years may come at a different point from S5 and S6, and I think we'll have to be cognisant and think about what that means for autistic children and those who care and look after them and I'm confident the education group will do that with your help and the feedback from your community.

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### Question

We had a few different questions about shielding. Some of the challenges for autistic people have been information about something that seems to contradict information about something else. There was one question about people who are in the shielding group but also might need exercise and are used to going swimming and other outdoor activities, and they are asking if you are in that shielding group what's the best way to keep yourself healthy and fit.

### Answer

Let's go right back to first principles here and it's not a great story if I'm honest. This virus is horrible it's absolutely horrible and it is particularly horrible if you are at risk of severe illness when you get it. So that's why across the UK we took the choice to create a group that we have called the shielded group. In Scotland that's about 170,000 people. We don't want to shield anybody so we didn't put anybody on that list lightly. We're asking them to really really sacrifice liberty and contact with others. We're asking them as much as possible even to physically distance from their own family and we've had to put in place support networks for food delivery and for medicine delivery. So it's really not something we wanted to do.

Don't get the shielded group confused with the higher risk group. That's the group of flu vaccine people; pregnant woman and those over 70. Shielded is special, it's not special in a good way so it's unusual to be shielded but if you are shielded you are at very very high risk if you get this virus. You're not at more risk of getting it but if you get it you are much more likely to have severe disease and the bad news is you are also much more likely to die of it. I realise that's really harsh but that's why the shielded group exists. Therefore shielding is the most important thing. Physical activity, exercise and well-being are, of course, important and we haven't done it without thinking about people's mental health and their nutrition and the sleep they'll need, but the most important thing is to protect you from the virus. So we really really want you to be physically active inside your own house or in your garden. Physically distance from others, we do not want you out connecting with any other people and I hate saying it, it feels wrong to have to say it. But that's the rules, I'm really sorry.

Now the other problem with shielding is that shielding doesn't all happen in nice detached Georgian villas in houses of two people with separate bedrooms and four bathrooms. I mean that's not how people live. People live with autistic children. People live with families of six, granny up the stairs and cousins next-door so we understand that shielding will not always be an exact science but the principles are you're at such a high risk that you have to be really really careful and we need you to try and do that. If you need to change your baby's nappy then you need to change your baby's nappy we're not stupid but you have to be as supported as you possibly can to shield from the virus. It's not a fun answer, but hopefully it's clear.

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### Question

The next question has got a couple of elements to it. This person's son has got a really intense fear, a phobia of needles and injections and will not be able to take medication in any form. He's very concerned about the testing and medical interventions that might be needed. Have you got any advice around how people who've got these particular anxieties are going to be supported?

#### Answer

That's a great question. The health and social care system is very used to doing that. My proper job, it seems like a long time ago now, was as a dentist and then a surgeon. I had a special interest in those with real anxieties and phobias. I spent a lot of my clinical time treating autistic and I think principally because I was a talker and I was happy to talk for a long time to people and that was usually the mechanism that worked. Communication and trust was the way to do that.

The present Covid-19 test is a cotton bud - that's what it is. Now that cotton bud has to go down your throat and up your nose so it's not pleasant. It's not quite as horrid as a blood test for some people. It's not pleasant but it's not particularly sore or damaging in any way so you might want to just describe that to people who are going to have to have it.

We've had to do a lot in care homes as you've seen in the last few days and weeks. We've started to talk particularly to those in dementia units, how to go through some of that training so that that might be helpful. It's literally a cotton bud in a sterile packet that we get saliva on. So it's not a needle, it's not anything particularly dangerous or sore, so that that might be helpful. And the health and social care system is very used to treating all comers whatever they look like or feel like so I would hope that that would be done in a compassionate and if it needs more time it needs more time. If it needs to be done fast it can be done fast but if not it can be done slower. And we can certainly look at drawing up some support materials around familiarising children and adults to have things that they are not used to, and some pre-warning of what that's going to look like would often help these families I would have thought.

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#### Question

A couple of questions now about social distancing and face covering. There is someone who has got in touch whose son is very keen to stick to the rules and tries very hard to stick to the rules. He has stopped going out because the anxiety of other people not sticking to the rules has become so intense for him. What's going to be done to ensure that people stick to the rules?

#### Answer

It's a fascinating insight isn't it, that autistic children in particular can often give you because the literal nature of the translation of what even I say out loud is fantastic. If only everybody were so literal and rule following then the virus would have been suppressed better probably some time ago.

It may be helpful to understand the science a little. The science of population health doesn't require a hundred percent compliance with interventions. So if I have asthma the asthma inhaler is for me. If I take the asthma inhaler I will be better. It doesn't do anything for you. Population health which is what we're doing here; we're telling the population to wear face coverings here we're telling the population to socially distance here. Population health needs a certain proportion of the population to do certain things. So if you obey the rules that's the right thing to do and I'm not telling anybody else then they get off without following the rules, but if you see people who are just not quite doing what you do then that's probably ok for the whole population which is what we're trying to protect and you as an individual are protected by your own behavior.

So it's important that you look after yourself and your family and those you care for, so you should absolutely follow those rules you shouldn't mix the households you should physically distance from other people you should wear face coverings in crowded areas, but you don't need to wear them in the street, you don't need to wear them in the park but you should wear them if you're on buses with a lot of people or in busy shops.

You should try not to get overly concerned about them or other people because there's nothing you can do about that and there's certainly no reason not to leave your house.

This virus doesn't like the outdoors so actually the outdoors is a good place to be. So gardens or for a walk- 30 to 60 minutes or so is actually a good place because the virus doesn't like the wind and the sun and all the things we get outdoors. You can tell from the care home information in the last few weeks that the virus does like institutions, it likes closed spaces. It likes places where there's poor ventilation, where there's a lot of people in close proximity so actually outdoors and being outside the house is a really good thing.

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### Question

This person has an autistic daughter who also has epilepsy and really cannot tolerate things on her face. People are a little bit worried that face coverings are going to become mandatory and if that's the case what will the exceptions be for people who are autistic and perhaps have sensory sensitivities?

### Answer

Let's be clear what the rules are just now or what the guidelines are just now. We are not overly convinced by the evidence around face coverings you can hear us in our language we're using, talking much more about hand-washing and physical distancing, we are certain that those things work. Whereas the evidence for face coverings is much much weaker, but there is some evidence in a symptomatic people that in crowded areas that may help us a little bit. However there's no obligation to do it and we certainly don't want people stigmatized or arrested or fined or even getting a row in the shops for not doing it. Even if we made them more mandatory, and we will only do that if the evidence tells us to do so, there would

always be exceptions for exactly that scenario you've just described. If people are unable to wear them because they have respiratory disease, because the thought of that enclosure in some way affects their lungs, or people with sensory conditions where they just can't tolerate them. They'll also be age considerations for example, if a kid can't do it and is actually taking it on and off all the time is more dangerous than not wearing at all.

I'm confident there will be exceptions, common-sense exceptions at every level if we have to do that and just know it's pretty limited places where we're telling anybody to do it. You do not have to wear them out in the street you don't have to wear them around your house and if you're going into Sainsburys or Asda and everything is spaced out properly there's not much benefit there either. If it's a bit crowded maybe in a corner shop or maybe in a supermarket at certain times of the day then we think there probably is some benefit from it and if we start to remove the measures and people are more on buses and in trains then again we're thinking that that might be a good thing for people to consider.

### Question

This question relates back to the schools. Some autistic people feel that their specific needs are not really being taken into account in the guidance and that they are having to try and wade their way through this general guidance and there's a little bit of worry about adapting that guidance for when the rules change. Do you know of any groups or any work that's going on pretty much like there is with education? Is there anything going on in the broader social care or social landscape?

### Answer

We are working with organisations such as yours and organisations that represent other groups of individuals whatever group that might be. The pace of this pandemic and the pace with which we've had to put things out has meant we haven't been able to do what we would normally do which is consult much more and translate into different languages have the sign language people come along and do their thing. We haven't been able to let people read the documents and make sure that they are understandable at every level. I have been on TV and the guidance has changed during the interview on TV, that's the pace of change we're trying to deal with here. That's not an excuse it's just an explanation of why sometimes people will feel when they go on the website and the guidance keeps changing.

So I accept that criticism I think it's completely fair. We should try and do that at pace as much as we can whether it's a translation into Hindi or whether it's an autism friendly version of that in video form or its guidance that you guys can help us do. Now there are some national organisations that help us do that, we've got health literacy as one of my policy areas so there's some really good people who help us with what health literacy means for the population and why an info-graphic would be good over here or why we need a long piece of guidance over here with real rules. We've got people in the centre who do some of that but were very reliant on third sector organisations to help us with that translation into whatever it might be whether it's independent living communities or the ME society or Scottish Autism and your partner organisations.

### Question

This questions if from someone whose son is obsessed with playgrounds, and would like to know when these are likely to open up again?

#### Answer

I can't help them I'm afraid. The rules are every three weeks we consider what we have to do. The seventh of May, Thursday, is the next one. I don't anticipate much happening. The 28th of May will be the one after that. In the document that we published this week around the next step, the decision-making framework, we did say that one of the things we are considering is more outdoor activity for families and individuals although it almost certainly won't be mixing families yet. It may be that you will be allowed out more than once. We've made exceptions for autistic people already to allow them to keep a routine of outdoor activity. The bad news is that surfaces are still a problem. So gateposts, benches, playgrounds are a risk, so we will be cautious about outdoor play areas. It may be you have to be a little bit innovative, take stuff with you that you have in your garden, if you have such a thing, or think about taking toys and balls and other toys with you.

I don't think first thing we do will be to open areas where kids and adults can touch the surfaces. I don't like that news but I think that's probably the reality of what will happen, I think it'll be staged.

#### Question

We've got an individual who got in touch about their son who is non verbal and needs really 24/7 support and they're very worried about should the worst happen and he has to go to hospital will they be able to go?

#### Answer

Yeah they will they will absolutely be able to go with them. I am the person who introduced Scotland's person centred visiting resume and it was it's one of my proudest moments when I wrote the letter to tell everybody that we were abolishing visiting times across Scotland hospitals. It was a fantastic day, and then six weeks ago I had to shut down visiting across our hospitals and care homes. It broke my heart, absolutely broke my heart, but there are exceptions to that visiting. Remember, that visiting restriction is for the safety of both the visitor and the patient and family because the virus is so bad. That's why, and it's not going to be forever, but there are exceptions in there around birth partners for pregnant woman, around end-of-life care, and around those who would find no visiting distressing. Now that might be dementia parents and grandparents for example who get very confused if they don't see a familiar face and also for people like that like your correspondent has just suggested.

What we would say is we have to do it safely, we have to do it in a way that reduces the risk as much as we can for your kid and you. You are not going to be able to take a family of six. I know that's not what the question asked but you're just not going to be able to do that so it's about probably single people, probably named individuals who can come and be with that person in a safe way.

You might be given some protective equipment to wear depending on what it is. If it's an A&E visit because there's a sprained ankle you won't notice much difference at all actually but if it's a four day visit because there's a burst appendix or some other

incident, I hope that doesn't happen, then absolutely you'll be able to visit but it'll feel a little bit different.

#### Question

Slightly related to that, is there any indication of when GP surgeries will open up for one to one consultations again?

#### Answer

No GP surgery is shut unless they've had to shut because they're running the hub, the covid hub, so what's happened is GP surgeries are running differently. So GP

The vast majority of surgeries are now doing much more triage on the phone or like this, with some form of videoconferencing which I think is a really good thing. I think we'll probably keep in place a lot of that infrastructure and help when people will be able to get quicker and more responsive answers, I hope.

Face-to-face transactions are still available but they are now much more risk adjusted so the nurses and the doctors inside those institutions are making the decisions about when and if that happens. If you need a face-to-face interaction with a doctor or a nurse in a practice that should still happen. You might find it's a slightly different version than the one you're used to it may even be in a different place because some of them have moved to different premises because we've put the covid hub in a practice but you shouldn't find a big difference in the service you're receiving in fact in many places the service has improved.

#### Question

Just going to close off now with a question that somebody sent in specifically for you. They wanted to know how you're coping with the pandemic which is very thoughtful of them.

#### Answer

Isn't it just, aren't they nice? It's good and bad, there's nothing good from a pandemic but I am finding purpose which I think is really important. I feel as though I have a job to do and people can judge whether they think I'm doing that job good or bad and some people on social media would suggest it's not all good. So there's the professional bit which I think is really important to me, it's important to have a purpose and I feel as though I have; both engaging with your organisation and being a little bit of the public face, the non-political public face, of the messaging and I think that's important because it can't all be the politicians. The First Minister is very clear it can't all be the politicians.

On a personal level I have very supportive wife, sister, and parents. My parents are not quite shielding but they're in the high-risk group so they are at home, in their late 70s with pre-existing conditions, but they're fed up with me facetimeing them! I exercise every day, I eat three nutritious meals mostly nutritious meals sometimes there's Doritos involved which is bad but I sleep well. I've always thought in my public health training that sleep was a hugely important thing that we underestimated. So I'm not a 5:00 a.m. riser that's for sure. I think if I do the basics well then I can pretty much work around the clock if I can get through it.

So honestly, people have it a lot, lot harder than me and my family I am very well looked after and the advice I try and give is balanced around those who don't have the advantages that I have of having that purpose and not be lonely and not having to deal with a family of five or a or a caring sitting with their the carer. I have it I have it pretty good if I'm honest.