

Written evidence submitted by Wetwheels Foundation and Rose Road Association (CVD0003)

Transcript of an interview on 12th June 2020 between Geoff Holt MBE (Founder and Trustee of the Wetwheels Foundation) and Juno Hollyhock, CEO, Rose Road Association.

Link to video: <https://www.youtube.com/watch?v=9DYIFbjQcIQ>

Contributors

- **Wetwheels** operate a network of purpose-built power catamarans around the UK enabling barrier-free boating to all disabled people. Wetwheels is a Sport England Partner. One of the groups Wetwheels work with are Rose Road Association.
www.wetwheelfoundation.org
- **Rose Road Association** are a Hampshire based charity offering respite care for young disabled people and outreach work supporting their families in the community.
www.roseroad.org.uk

Summary

It is clear that C-19 is having large and disproportionate impact on those people with most the complex disabilities and for those who care for them. Specifically changes to routines and procedures leading to ‘anguish’ for those young people who can not process nor understand those changes. Concerns exist that the easement from lockdown and the renewed changes to routines and procedures will present similar challenges.

It is also clear that much emphasis is placed on re-engaging these young people with outdoor activities, particularly those which help increase confidence and reduce anxiety. Wetwheels is one such partner with whom both organisations look forward to recommencing activities, albeit in a modified format, as soon as guidelines allow.

Essential Reading

Whilst it is recommended the transcript is read in its entirety, there are specific paragraphs within the document we would wish to highlight as essential evidence for the Government Inquiry. These have been underlined for ease of reference in the document.

These specific paragraphs are also for the benefit of Sport England as they demonstrate the importance of Wetwheels in supporting people with complex disabilities and how we work with partners like Rose Road Association.

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Geoff Holt:

1. Welcome everybody for Wetwheels Solent's first live stream. For those that don't know, my name's Geoff Holt. I am a trustee of the Wetwheels Foundation. I founded Wetwheels, nine years ago now.
2. We've all been in lockdown for a number of weeks and months now, and some of us more than others. The trustees have been talking about what life must be like for our participant groups, our disabled participants who come on Wetwheels with us. It's all very well talking about it amongst ourselves, but I thought the best thing to do is actually to speak to someone who knew exactly what that meant and that person was Juno Hollyhock. I'm delighted that Juno is joining us today. Juno is the chief executive the Rose Road Association. I thought rather than me tell everyone how wonderful Rose Road is and what Rose Road is, over to you.

Juno Hollyhock:

3. Thank you, Geoff. Thanks for having me. It's really interesting. It's a new, first time experience for us as well here. The Rose Road Association, we're a Southampton based charity serving Southampton, Hampshire, Portsmouth, and neighbouring counties. We provide support by way of 24-hour respite accommodation, overnight respite accommodation for children and young adults with profound and multiple learning disabilities and physical disabilities. Increasingly we're picking up some quite complex health needs as well. We also provide outreach in the community services, play schemes and activities, and we have helplines for families who are struggling with some of the issues around disability. We provide the independent advice and support helplines for those families. That's really in the neighbouring counties, as well as in our local counties.

Geoff Holt:

4. I should declare I am an ambassador for the Rose Road Association. I have been for 14 years now, and I'm very proud to be so.

Juno Hollyhock:

5. On our site at the Bradbury Centre are two residential homes, and it's the base and the hub of our operations. When COVID-19 started, we all went into lockdown. A lot of organizations had staff homeworking, for example, but a lot of our family support staff already home-work. We've got families there who are home-based or who work out in remote temporary offices, providing all the telephone helpline support. For them, it was almost business usual when we moved into the lockdown position, but for the staff that are used to working out at the Bradbury Centre, and we're located just 10 minutes walk or two minutes drive from Southampton general hospital, to give you a sense of where we are over there in the west of the city.
6. A lot of staff suddenly had to go into a homeworking environment which was quite challenging, but equally because we didn't close our services, we've had a lot of staff that had been coming into the building all the way through, right from day one of lockdown through to today. We've got 15 beds covering both our children and our young adults homes. They're two separate homes, separately registered, one with OFSTED and one

with CQC. We have two separate regulators. We probably have about 150 families on our books for the overnight residential care, and we probably have a smaller number, probably 50 to 60 families who use our outreach day services community support. And all of those are based and located from the Bradbury Centre. Although community outreach, up until lockdown, was as it sounds, getting out and about in the community and accessing community facilities. It's obviously looked very different since we've been in lockdown.

7. Those young people have been coming into the building. In terms of how many have been accessing throughout the COVID periods, we did experience a massive drop-off, not actually from lockdown but actually in the weeks running up to that, families who are very concerned about the health of their loved ones and felt that to expose them to any kind of environments where they are interacting with other people perhaps wasn't going to be beneficial. Perhaps it was going to put them at risk.
8. This was very early days, when we didn't really understand all of the infection prevention and control measures that we could put in place that would help to keep people safe. It's been very much a learning curve. As we've gotten better along that learning curve and improved our procedures and processes, families have been coming back to us. The initial drop-off was probably only actually about 50%. We expected to see an empty building when this first happened but that's not what happened. We've also taken some additional placements at this time, families who've really, really been struggling because their school place is no longer available to them. We've given them additional nights, additional day services, hours, and additional community outreach hours, although as I said, community outreach looks slightly different now.

Geoff Holt:

9. I wanted to explore now a little bit about the impact of COVID on your service users, the young people with PLMD. These are vulnerable young people aren't they? They have multiple disabilities.

Juno Hollyhock:

10. Yes. These are people that we tend to describe as profound and multiple learning disabilities and physical disabilities, physical disabilities that sit alongside learning disabilities, but we're not really talking about a single diagnosis here. We're talking about young people who are living with very, very complex conditions. These often complex conditions that run alongside health conditions as well, that develop and change as people grow older. Somebody who might start out with say a relatively low level epileptic condition, those seizures might escalate as they get older, and they might then become vulnerable to other health conditions, cardiac conditions, probably digestive conditions, all sorts of things.
11. It's a changing picture for a lot of these young people. As medical science develops, some of these things are treatable. Some of these things are not treatable. People are in a bit of a shifting environment, but they are very complex, our young people. A lot of them use wheelchairs. A lot of them don't use verbal communication. For example, a lot of them

have an element of developmental delay which means that understanding context can be difficult, which obviously at this time is a real challenge.

Geoff Holt:

12. I was going to ask that. The context now with the change of routines, the change of what they're used to doing, and I'm guessing with care workers maybe wearing PPE, and all of these changes, I'm wondering what impact that's having on the young people.

Juno Hollyhock:

13. Absolutely massive. We've noticed that with all the families that we engage with. For those families that can't come into the building, we are engaging with some of them online. We're doing experiences like this, having a digital interaction, a digital exchange which we might proceed by sending out some packs of activities or games that we will then do with them online. For those young people, their lives have completely changed. They had very set routine. They probably had care staff coming into the home at the beginning of the day. They then perhaps went to a day services or a school or a college setting, that came in the evening possibly then attending some supported activities, interest activities, theatre, drama, for example.
14. All of that is now shut down. All of that infrastructure around that family, that helps that family to keep going, that helps those young people to thrive and to grow and to develop, and gives them a sense of routine, has been disrupted. It doesn't mean it's been completely removed. There are still domiciliary care providers providing that care within the home. But, as you say, they may be going in wearing a face mask and a face visor for example, which might not be something they had to wear before. If you're working with somebody who finds any disruption in routine a challenge, to then put them in a position where they can no longer see or interpret the facial expressions, or even hear properly what their carer is saying to them, it's not just disruptive. It's anguishing. I don't use that word lightly, because what we see is the anguish, that this causes for our young people, leads to an escalation in behaviour as a form of communication.
15. Behaviour that says, *"I'm struggling. I don't like this. My routine is disrupted. I'm not seeing the people that I usually see. I'm not going to the places that I usually go to. I have no idea why. People are trying to tell me things and it's not within my realm of understanding. And now, the people that I am seeing have this weird thing on their face and there's lights reflecting off the visor and you've got this band around your head. And it's very, very challenging."*
16. We see escalations in behaviour as a form of communication, behaviour that might look to the outsider to be aggressive but it's actually upset. It's anguish behaviour. Also, we're seeing the impact on mental health and indeed some of the physical conditions, potentially an escalation in seizure activity for example. We all know that heightened levels of anxiety can lead to a heightened heart rate, can lead to all sorts of physiological changes within the body. That then shows itself with very physical manifestations. All of that is going on, and we can't tell our young people when this is getting to end. For some of our young people, the concept of time is too fluid to understand that anyway.

17. We just have to work in the day, in the moment, but recognizing that somebody, for example, who maybe is somewhere on the autistic spectrum and has a number of other conditions that they're living with, we might normally work with them on a one to one basis, but if they're really struggling and incredibly anxious, we might have to put two staff in to support them because then we can keep them safe and we can keep the people around them safe.
18. But actually, even by adding that staff member, once again we've disrupted that routine. Once again we've made their environment different. Whilst we're keeping people safer, we're also adding to the problem. It's huge. It is painful to see people just not understanding why they can't see their friends. There's no rational explanation we can give them. There's no Makaton to explain the pandemic in a way that's understandable. There is Makaton to explain the issues around a pandemic, but those global contexts are very, very hard to communicate.

Geoff Holt:

19. For those people who don't know, Makaton being-

Juno Hollyhock:

20. Sorry. Makaton is one of the nonverbal communication techniques that we use. If you see people working with young people, you might see them do that (makes a hand gesture from the mouth), which is Makaton sign for thank you. It's not British sign language. It's a form of sign language that people quite often use for learning disabled young people.

Geoff Holt:

21. Juno, at Wetwheels all of our boats are currently locked down. We are all tied up to the dock and me, along with all of our volunteers, are frustrated by that, we want to get out onto the water again. We have been thinking about how that happens. A lot of funders who fund us are asking questions about, "*Do you really need the funding now? Is it important now? Surely it's important to give it to frontline services.*"
22. In our hearts we know that we're going to play our part once easement commences, once we start coming out of lockdown, particularly for groups and organizations, like the Rose Road Association. We're beginning to think about how that works. One of the reasons I wanted to talk to you is, it's all very well thinking how that works and thinking is it the right thing to do? Is it what young people need with disabilities?
23. That isn't a leading question, but I'd be delighted to hear what your thoughts are. I thought, after you've said that, I'll share a few pictures of happy times on the boat that we can talk through, but just generally around your thought processes around easement and the importance, not only on mental and physical health, but just general wellbeing on getting out again and doing activities like Wetwheels.

Juno Hollyhock:

24. At Rose Road, our activity program is the epicentre of what we do. It is fundamental. We have a vision that wants every young person, regardless of their ability or disability, to be able to experience as many life chances and life opportunities as they possibly can. For our young people, they are often not exposed to experiences like Wetwheels. People often make the assumption that this isn't something that they can do or something that they can access. When they get a bit older and they can make a choice, they don't know they can choose these things because they don't know they would enjoy them.
25. We have found a reduction in available activities for our young people to be really, really challenging to manage and one of our first priorities as we come out the other side of this, and it's different for us because we have kept going all the way through, is to get back up with those activities that those young people used to do, however we can do it.
26. From our point of view, getting out on a boat in the Solent is going to be one of the safest things that we can do with our young people that has the richest, most concentrated experience we can possibly offer them. Experiences like Wetwheels are right at the top of the list, because even if what we have to do is something slightly different, if we can't bring a group to you, if we have to bring one person and find a way to cover the cost, and then take it in turns to do half-hour experience, rather than a 90-minute experience, for example, the benefit that will give that young person, it's... We have to think the young people, that we work with, work in a sensory way which perhaps we don't necessarily understand if we don't have PMLD and we don't have any kind of sensory impairment.
27. I don't always think about the feeling of the wind on my face. I don't always think about the smells that I can smell. These young people depend on those senses because not all of their senses necessarily work in a full way. An experience like Wetwheels gives them access to tastes and touch, to scent, to sounds and all sorts of things in a way that other experiences just plainly don't. That's absolutely essential.
28. We need to start bringing that back because we are running the risk now of having young people who are desensitized to the tension of sensory experiences because it's been going on for so long. If you remove sensory experiences from people for too long, then it'll take time to build those up again. The funding is going to be an issue and it's absolutely right that the funds that are available go to the frontline services that are saving lives and protecting people. We absolutely support that. But we will be looking at our program of activities to make sure that where we do have funding, we prioritize those things that give the absolute richest of experience. That's where we'd be looking to experiences like Wetwheels to help us with that.

Geoff Holt:

29. Thanks, Juno. It's very pleasing and rewarding and moving to hear you say that, because that is fundamentally what was at the core of when I set up Wetwheels. To someone who doesn't necessarily understand how we work, it's not just a trip on a boat. It isn't just a trip around the harbour. I remember people telling us, who have various impairments, that they're getting the sensory feeling of just the vibration of the engines and that sense of

acceleration which they can feel. It impacts different people in different ways. It's lovely to hear you say that.

30. We've got a rule at the moment. No boat is going out while social distancing exists as it does. That may change in time. That may come down from two meters. I think two meters is a bit challenging on a boat. We're really giving thought how that works with life jackets. Maybe the care worker puts the life jacket on the young person under supervision. We clean, antibac, wipe down lifejackets between trips and wipe down hard surfaces.
31. As you were saying earlier, maybe it's fewer than 10. Maybe it's one or two people per trip and we adjust the trips. I'm speaking from someone who's not left my house for 80 days. And I can articulate myself and I can comprehend what is going on, and even I feel sad at times and confused by the uncertainty. I know that I'm going to need to get out on the boat. I just want others to share that.
32. We talk about the joy of the sensory experience of being on the boat. For some people, it's just putting their hand over the side of the boat and feeling the spray. For others, it's that feeling of wind on their face.

Juno Hollyhock:

33. I think too, Geoff, one of the things that's really important for all young people and will become even more important as we come out of the scenario where they have had no control, even less control over their lives than they would normally have, you give them the opportunity to drive the boats. That is profound. To give our young people the chance to lock their wheelchair in or move themselves up to that steering wheel and take control of the direction of the boat. It is profound on a number of different levels. I think again for us, that's one of the reasons why you'd be a priority activity because there's very little else that they can do that gives them that feeling of control, that power, that decision making, so, so important that this time when there's just nothing they can do to stop the horrible things happening around them and the way that they feel because of the current situation.

Geoff Holt:

34. Young people, are they leaving at all at the moment at Rose Road? Are they going out on any trips at all or is everyone locked down?

Juno Hollyhock:

35. It changes week to week. In the early weeks, they really didn't leave the centre much at all whilst they were with us. If they went anywhere, just we've been to a local green space slowly and on an individual risk assessed basis, because every young person has different vulnerabilities. Also, we want to make sure our staff are comfortable with what we're asking them to do as well. On an individual basis, we've decided some have been able to go and maybe get a takeaway coffee or a takeaway bite to eat or something, and then go and eat that. We're beginning to explore what's available. As more retail outlets open and more leisure outlets open over the next few weeks, as easement happens, we will look at

what they can go and do, but I think we're all agreed as an organization that our priority will be towards outdoor experiences because it's clearly lower risk.

36. We'll also be prioritizing the experiences that we know have a direct connection with an improvement in levels of anxiety and mental health and wellbeing, for example, in self-esteem, because these are the things we know we're going to have to work on quite intensively over the next few months. While to some people shopping is a fantastic experience, that's something they choose to do and really enjoy doing and we would never stand in the way of that in normal times.
37. Where I think we know we have anxiety issues and mental health and wellbeing issues that have built up over the time, it's important that we look to address those first. As we know through studies, that you and I have been involved with, with the Wetwheels experience, there are direct correlations between going out on the Solent, experiencing your local environments and having that very physical but also quite intellectual challenge, and how you then feel about yourself afterwards. We've seen some very positive results with that. I think that guides us towards that type of activity because we will have a backlog of mental health and wellbeing issues. We're very aware of that. I think with our client group, we don't know what that's going to look like.

Geoff Holt:

38. That will only manifest itself in time.

Juno Hollyhock:

39. It will do because actually for some people, this has become their new normal. They may not understand the context. They may not understand the PPE or the measures or why they can't do or see the things they've been doing or seeing before. But actually, we're going to go through an easement process that equally they will not understand and things will change with them again. It's going to be the same transition.
40. I think actually, a lot of us are feeling that. We've got used to where we are and it's almost scary now going to the new normal, as it was coming into the COVID situation and lockdown. At least we can rationalize it and understand it a little bit more. Whereas for some of our young people, that's not very easy to do. I have to recognize we've got yet another transition, that might actually trigger more anxiety and mental health concerns.

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