FROZEN LIGHT

The Frozen Light Podcast

Episode Four – Interview with Rachel Wright from Born at The Right Time and family Carer

Lucy (00:00): Hello, and welcome to the Frozen Light podcast. A podcast aimed at staying in touch with the PMLD community in the age of coronavirus

Jingle (00:08): [Jazzy Music].

Lucy (00:20): So I'm Lucy Garland and I'm one of the artistic directors of Frozen Light.

Amber (00:24): And I'm Amber Onat Gregory and I'm the other artistic director of Frozen Light.

Lucy (00:29): At Frozen Light, we usually create multi-sensory theatre for audiences with profound and multiple learning disabilities.

Amber (00:37): Now that the theatre scene is currently on pause, we are making a podcast to stay in touch with the community we usually perform for at this time.

Lucy (00:49): So we've got a really exciting episode for you today. But before we introduce our guests, we just wanted to let you know that we are still looking for people to join the audience panel. And this is an opportunity to be a little bit more involved with Frozen Light.

Amber (01:03): We're looking for people with PMLD, their carers, parents, support workers, people who work in the PMLD community to come and support Frozen Light with the next adventures of the organisation.

Lucy (01:15): So on today's show, we've got Rachel Wright who runs Born at the Right Time- it's a blog, it's a website, she's a trainer, she's a former nurse, she is mum to Sam, she runs Camp JoJo. She's a very busy woman and we are very lucky that she has an hour in her schedule to take out and speak to us.

Amber (01:39): We're really excited to speak to her today. We first came across Rachel, when we heard her speaking at Raising the Bar conference about Camp JoJo and me and Lucy were so excited about hearing about the camp. We are both huge campers and we would love for Frozen Light to be involved with Camp JoJo in some way in the future.

Lucy (01:58): So let's give Rachel a ring.

Sound Effect (02:03): Phone ringing sound

Lucy (02:03): Hi, Rachel, thank you for coming on the show today.

Amber (02:06): We're really excited to have you here.

Rachel (02:09): Thank you for having me.

Amber (02:11): Um, so Rachel, would you like to introduce yourself and Sam?

Rachel (02:16): Sure. Well, um, I'm Rachel, I'm an asthmatic with a bit of a bad back at the minute. It kind of starts the bottom part of my back and shoots down my right leg. I've got eczema, I've got hay fever, broke my wrist last year and then ruptured my APL tendon, and I need to have surgery!

Lucy (02:40): (Laughs).

Rachel (02:40): And Sam, well, Sam's a 14 year old brown haired boy with bright blue eyes, for some reason, all of my boys have got blue eyes except I've got Brown eyes. How's that even a thing? Um, his favourite things are music and swimming. Pointless, he's a big... Pointless-. Alexandra Armstrong and Richard Osman fan. He prefers Lucy, the carer that's living with us, to his own mother, and can regularly be found blowing her kisses across the room. Erm, he's missing school, but he's delighted that lock down has meant that we have been persuaded to buy an inflatable hot tub so that he gets exercise and physio. Um, and so he has a really healthy tan with a very definite trunk tan mark.

Amber (03:29): Amazing!

Lucy (03:29): That's what every teenager needs. A trunk tan line.

Rachel (03:33): Exactly. He's rocking it, seriously.

Lucy (03:38): Oh, amazing, I'm pretty jealous of Sam's hot tub.

Rachel (03:42): Yeah. Yeah.

Lucy (03:44): So tell us, what does your look down look like and how has life changed for you?

Rachel (03:50): Well, obviously lockdown's, just wonderful, and it's fantastic being confined into a small space with three children. And, uh, you know, who love to move things around the house and expect some mystical creature to magically transport it overnight to where they might find it the next day.

Lucy (04:11): (Laughs).

Rachel (04:11): Erm, and obviously they don't have any screen time because they are out exploring nature, and they are having sensory experiences and just soaking up this real quality time with me. Obviously that's all utter nonsense.

Lucy (04:29): (Laughs)

Rachel (04:33): Erm so I have thought about starting a YouTube channel where I, erm, like, show people messy places and sort of say, 'Look, if you close the drawer after you've used it, it doesn't look so bad. And, and when you take clothes off, you can like put it into the laundry basket afterwards.' Erm, in the hope that they might, you know, the amount of YouTube they're watching, they might randomly come across them. And somehow miraculously discover that, you know, things can be done without me shouting at them or instructing them that it is required. No, really what's lock down like...lock down is... Well before lockdown we had like nine carers. Some of them just did a one or two hours every couple of weeks. Some of them did a couple of nights a week. Erm, but I, we managed a team of nine carers when lockdown properly came into place, when Boris Johnson did his whole sitting in front of the table thing, erm, then we decided to go it alone, try to go it alone. Erm, and I'm really proud. I survived a whole two weeks! A whole two weeks!

Lucy (05:39): That's impressive!

Rachel (05:39): I know, I know you have, I know you've spoken to other parents who have done much, much longer than me, but I honestly two weeks of doing the nights and the day. You know there is a reason I didn't become a primary school teacher, a secondary school teacher, or an SEN teacher.

Amber (06:02): We say that a lot to each other don’t we Lucy?

Lucy (06:02): We do. We're like 'this is why we're not teachers.'

Amber (06:02): It really is a specialist role!

Rachel (06:11): Yeah. So after two weeks, um, we managed to persuade a wonderful carer, Lucy, who like I say is flavor of the month, actually with all the kids to be fair. Um, and you know, given the fact that we get sleep and slightly more fun for our kids as well, she's pretty high on our list as parents as well, Tim and I. We did two weeks without Lucy, and then we've had Lucy in, but nobody else. So she's been isolating with us. For me, that meant- I do a bit of running, I've run a couple of marathons. I haven't run a marathon for a couple of years, but going into lockdown, I quickly realised within a couple of weeks, that it was like I was going on my marathon run without taking any of my energy gels. And although I could get round it, I'm going to be an absolute mess at the end of it. So I just kind of, you know, we kind of came to the point, and I think is what parents like me have to do all the time. Is 'yeah, we can get by, I can manage to not kill my children. I can manage to not throw any of them out the window, I can manage to, you know, not harm myself, but is that the best I can, I can offer them? Is that the best I can do?' And actually, um, I think it's hard, isn't it to, to ask for help. Um, but I absolutely recognise that when I get more sleep, I'm a nicer person. I think lockdown was, er, has been difficult because my world has shrunk again, you know, like we said, the whole teacher, um, and the work that I was doing before and stuff, um, and you know, I like talking to people and, and that's shrunk, that world shrunk. And so that's been, that's been difficult to kind of process a little bit, and then process because it's a new thing, but also process, cause maybe it's opened up some past trauma as well, those first few months, and years of Sam's life, where all of our dreams and hopes and expectations that we'd had, we're completely sort of taken away or changed. Um, I think the lockdown has kind of brought all of those emotions back up to the surface. I kind of , I wonder whether we've got like, um, emotional memory, you know, the way like my son tries to play the violin. Oh my goodness. You know, talk about being, um, I'm in lockdown with someone learning the violin, anyway, (laughter) but yeah, he has his violin teacher talks about muscle memory, like if you do that thing over and over again, and you'll learn it. And I wonder whether there's been so many times when I've been, erm, standing at the hospital and getting more bad news, and having a plan for going on holiday, and my child gets sick and it stops and you know, all these things that you expect. And so I think there's been something about this episode of, of lockdown that has brought a lot of those really difficult emotions that I've dealt with as much as I can, back to the surface and made me kind of revisit them, and work them all out all over again.

Lucy (09:28): And you're not the first person we've interviewed that said that actually, interestingly, our last week's guest was saying exactly, exactly the same thing.

Rachel (09:37): Yeah. Yeah. There you go. We must be right then.

Lucy (09:41): Yep, always! (Laughter)

Rachel (09:45): Yeah. And I think it's a challenge though, isn't it? Because, um, I think lockdown has been the easiest bit to be fair because we've had really clear, right, 'This is what we need! To, to make it okay, this is, this is how you keep your family safe. But we're now in a situation where we have inevitably got months, potentially even years of a new type of normal, with social distancing and shielding and isolation, and all these jargon words that none of us even knew, six months ago. Um, another similarity with becoming a parent of a child with complex needs. Erm, and we're going to have to work out how to look after our families all over again, because funnily enough, none of the guidance, really, kind of relates to us. None of the guidance really, you know, speaks into our individual systems/situations. And so we have to, um, we have to risk assess all the time, which is, you know, we we've done for years. We've, we've got to work, we've, we've spent our lives risk assessing, erm you know, whether to leave our child with another person or whether to go on holiday and decide how far away that is from the hospital or whatever. Um, and so I think we're used to making those risk assessments every day. Erm, but we're going to have to do that, erm, very deliberately and very carefully over the next, over the next months and years.

Amber (11:17): And today is Tuesday, the 23rd of June, and it was just yesterday when new guidelines came out for people who are shielding and who've been told that they need to shield, that, can end on the 1st of August, as long as there are safe measures put in place, but that was basically the only information that was given. So what are those safe measures? How will that happen? How safe is it? What is the science, you know, so that new date's been given with very little further information.

Rachel (11:53): Yeah. And the other thing that's come out is the Royal College of Paediatrics and Child Health has revised their guidance as well. So when I talk about things being specific, actually those, that guidance is much more helpful to parents like me than sort of, um, the government generic guidance. Um, because it doesn't generally talk about children, it talks about adults. The difference in that guidance has been revised, and updated, is that actually, um, they've taken some of the children, so they've got two groups, they've got Group A and Group B. And Group A, is, um, talks about children who definitely need to be shielded, you know, and they tend to be children that are being treated with cancer, they tend to be children who are immunosuppressed, post-transplant children, those very clear cases. And then there's group B, um, and previously in Group A, Sam would have come under group A, he would have come under a child who might have difficulty swallowing, or maybe have some breathing difficulty, you know, sort of chest stuff. But he has actually been moved to Group B, which are, erm, these people may need to shield or not, actually, it's more likely they don't and they need to consult their clinicians specifically to discuss what that means. We didn't actually ever get a shielding letter. And I suspect that was really because, um, everybody thought somebody else was doing it, more than anything, rather than that it was the right thing. Um, but that was fine cause we were always going to go and do (laughter) what, we thought clinically was the right thing to do. My husband’s a GP, I'm a nurse. So we were always going to kind of risk assess and try and work things out ourselves. Um, but it is really hard, like you say. So for example, we've made the decision next week to start having a couple night carers in, so only two of our night carers, we're still gonna limit the personal care. They're not gonna, um, uh, I'm going to put lots of different things in place. For example, they'll come into the porch and I'm going to give them some blues that I've washed, as in some theatre blues, that I'll have washed. Now, they will get changed into those and they will wear a mask and they will stay two meters from everybody else in the family, and they will, um, when they're dealing with Sam, they will obviously had washed their hands as soon as they arrive and stuff and they'll put alcohol gel has soon as they go to him and they'll be wearing a mask when I deal with him. I mean, that's, that's not perfect, but I'm basically going to treat those carers as though they do have it. As though they do have Covid, and basically try and limit the potential for them to provide any infection. Again, for that reason that I said before, that this is going on for a long time and this might be the lowest infection rate we have for ages, because we're going to be releasing, we're releasing the population into the wild again! And goodness know what the pubs are going to be like when everybody realises they can go again. Um, and it's gonna get, it's gonna get hard, you know, the infection rate, it's going to change and it's not going to get a lot lower, so we have to deal with it.

Amber (14:58): And you've just mentioned that you, you're a trained nurse. Are you currently working as a nurse?

Rachel (15:04): No so I stopped, nursing outside the house? So to speak, when my youngest was born five years ago, um, I still registered as a nurse, so I'm, because of the training that I do and the work that I've done, um, around the communication coproduction stuff. Um I still manage to persuade the NMC that I am working. Um, although, you know, I know plenty of nurses that do a heck of a lot less nursing than I do at home, and I hell of a lot less nursing than a lot of other parents do, quite frankly. I reckon there's probably been a lot more nursing going on in the lives of complex children's homes than, you know, cause quite a few of the nurses. I mean, our, our palliative care nurses have been stopped from going into our house. So, you know, I don't know how much nursing you can do virtually on the, on the, the, over zoom. I mean it's possible and you can, but let's be honest. It's the parents and the carers that are stepping in and, and doing the care and the hands on changing pegs and, you know, buttons and Mickey's and putting NG tubes in that gets yanked out and doing the suctioning and all that stuff's being done by, by parents.

Lucy (16:21): And I think that's a really, you know, important point to make like how important parents and carers are, and even more so during this time, and how often undervalued you all are.

Rachel (16:34): It's something I talk about in the training, actually, you know, if you, if, no matter who you are, whether you're a physio and OT, a therapist of any kind or a specialist, if you go into a situation and you do your thing and you do it at the person and at the family and at the parents and stuff, and then you walk away, it will only ever last for that moment in time that you are present. If you build a relationship with the parents and the family and the child, and you build an understanding of what it is you're doing, and most importantly, why you're doing it and you inspire and you motivate and you resource the family, we will walk over hot coals for our kids. You know, we will do whatever it takes for our children. And if you tell, if you inspire me and tell me why something needs to be done, I'll be doing it at 11 o'clock at night or four o'clock in the morning or three o'clock in the afternoon because I'm there, and I can. So rather than, um, you know, simply, you know, the specialist doing their thing and then wandering off, there's so much opportunity. Um, and that's, lock down to expose that dramatically.

Amber (17:50): You've just mentioned your training there, so during lockdown you've started a course titled "re-imagining communication and co-production with families in a post COVID world", along with the hashtag bridging the gap. So how did this come about and what are your aims with the training?

Rachel (18:08): So I've been doing training. I sort of, um, you know, stumbled into doing this a few years ago. So I published my book, The Sky's I'm Under, which is a memoir about becoming a parent of a child with complex needs. Um, I stumbled into that. I, I had no intention of writing it, I got a GCSE. I got C in my GCSE English. I completely made up the reading list based on films that I'd watched, because I didn't read anything except the back of a cornflakes packet, um, and only if that, I thought It might have a toy in it. But I got to the point a few years, quite a few years after Sam was born he was probably seven or eight. And my head was just full, of the stories of our life and the decisions we made and the conversations we'd had. And I kind of just needed to get it out. Cause it was keeping me awake, not at night. My head hits the pillow. I'm out, wake up at five in the morning and I can't get back to sleep. So I, um, just needed to get those voices out of my head. So I started writing, did a couple of writing courses and did some blogging, and then the book was published. I self-published the book. Um, and from that people started again, having bridged both sides of the fence, you know, both sides of the bed, so to speak, you know, I've been the parent um, and I've been the nurse and I've been that healthcare professional who's broken the bad news. Um, and I've been the, um, the mother. So the bridging the gap thing is about, I recognize when I became a mum that there's a big disparity between the information professionals, get and the information parents get. And there's a, there's a, there's a conflict very often there's a tension, um, that comes about from different perspectives and different priorities. And I think the, that my dream is that we bridge some of that gap that actually, um, and I, I think there's this post COVID world is a fantastic opportunity for us to all reflect and reimagine and work towards, um, better understanding each other's roles and how together, we can be doing something, um, more, um, for each other to make life better for the children that we, we all care for at the end of the day, because we spend much time fighting and um, you know, me included the complaints, whatever. And I just think we could be using our energy so much better.

Lucy (20:57): Well, it sounds awesome. And it sounds like a much needed course and you get out and work, with doctors and nurses.

Rachel (21:03): Yeah. So the course's used to be like, you know, with real people, like and I used to like touch people.

Amber (21:09): Oh remember that!

Rachel (21:09): I used to like, um, so I did, I did communication co-production has been my, um, passion, I guess. Um as you can tell um, I don't like to talk. Um, and, er, but I, so I had something about, I just really feel like we could be seeing each other better from a professional and parent point of view. Um, and I do think that's two ways. I don't think that's just about professionals changing, how they work. I think that's also about parents recognizing that pretty much everybody who goes into the work that we come in contact with are doing it because they care, they're doing it because they wanted to make a difference positively for people's lives. Um they don't wake up in the morning and think, how can I tick off that women whose child severely disabled today, that might be what happens? But it is rarely the intention. So I used to do that physically, and it was like OTs and physios and medical students, nursing and postgraduate nurses. And I've spoken at international conferences, I've spoken at parliament and spoken in sort of just local events and stuff. Um, and yeah, those first three months of lockdown, I kind of had a bit of a, part of my meltdown and my shrinking of world, was like, Oh my goodness, the business that I've tried to build up over the last three years has just evaporated. Cause I can't go and do this stuff, partly because I've got all the blinkin' children at home. Um, but also, cause I can't, we can't do this traveling and whatever, and I have to consider the needs of the kids and keep everybody safe. Um, but out of my own, you know, in the same way I'm suggesting professionals reimagine, actually the process of taking the courses online. It means that the course on Thursday that we've got, um there's people from all over the country coming, there's people from all over the world coming, actually there's Australia, New Zealand, Canada, and all around the UK. Um, are coming on a course that, I mean, I couldn't physically, if I had to go to those places, there's no way I could see all those people. So actually that's one way that the virtual world is enabling me and I don't have to, I don't even have to get dressed, you know, as long as the top half of me, I can be wearing my pyjamas underneath the desk, and still, I can pretend to be professional and train.

Lucy (23:35): But, um, Rachel, we first came across you when we heard you speaking at Raising the Bar last year, about what sounds like the incredible Camp JoJo initiative, that me and Amber are like desperate to come. Um, so can you tell us a bit more about this? And obviously I've seen, it's been cancelled this year and how the plans have had to change.

Rachel (23:57): Oh, it'd be so fab if you came, that'd be awesome. Um, we, yes. So camp JoJo, is totally a dream come true for my husband and I, we, um, well, let's be honest, he loves the outdoors, I kind of grew to love it after being together for 25 years. Um, and he... I dunno. I don't know if you do camping at all.

Lucy and Amber (24:24): Yeah, we love camping.

Rachel (24:24): So, but that's the whole kind of, you think your car is quite big until you go camping and you're like, Oh my goodness, all this stuff. I remember when Sam was little and we'd go to my parents in law's house and we'd just be going for the afternoon and they'd be like, are you moving in? Because we'd have, you know, the baby bag with all the changing things and the milk and the meds and the different highchair that Sam could sit in and the specialist push chair. And that was just for an afternoon. So like taking kids camping full-stop is like, you know, you kind of need to get forklift truck and taking your child with a disability, camping. The amount of kit you have to bring is ridiculous. You spend more time packing and setting up, than you do actually there, we used to go for two weeks camping, but partly because you just felt you spent three days setting it up, you know, a day packing at home a day, traveling a day, setting it up. What was the point of only going for like a week, because then you'd be taking it down again. So camp JoJo is all about having all of the equipment and the support, we practically with people too, make camping actually fun for the whole family, not just the children and the parents are exhausted right at the very, at the very end. So camping was always really important to us as a family.

And we wanted to produce something that was actually a holiday and enjoyable for families. Um, and it is sadly one of those things, like, you know, just saying how helping, the potential for this virtual world to potentially, um, enable people, you really can't camp on a zoom call, in the same way. So yeah, we took the decision fairly early on that there was no way we were going to be able to offer exactly what we would have planned, which is seven or eight families in a private farm with all the facilities and equipment and volunteers they would need in order to have a really unique, fun, um, a new experience. But, um, we're hoping to offer a little bit of virtual stuff this summer, where people can connect to our Camp JoJo Facebook and websites, where there will be videos and some interactive things like, storytelling around the campfire and different bits that our volunteers and stuff are going to provide. Um just to make sure that everybody, knows that we will be back. Um, and no doubt, I think even next year, I think it will look a bit different and we will have to, we'll have to, um, adjust the way we do things. Um, but we're absolutely determined to, um, keep that dream and that passion and that experience alive for our families.

Amber (27:23): I think we felt very similar about multi-sensory theatre, haven't we Lucy? It's just like, Oh, we've done a lot on Zoom. We've even managed to kind of start a project with an organization in New Zealand, you know, that's all things that we wouldn't have considered to do virtually at this time. So there are things we've been able to do, but the main premise of our organization, we just can't do. And that's been really difficult.

Rachel (27:50): Yeah. Yeah. So I think when, when it's, when you're reflecting on things that, um, have changed, like for example, with families, you've got this inner circle of people who used to touch our lives physically every day, you know, there's daily carers and those, those teachers and those people that did transport, who absolutely touched our lives, not just in a metaphorical sense, but in a very physical, practical sense and lockdown has utterly stopped that from happening. And there isn't a, you know, there, isn't a way of replacing that, that sort of outer circle of people who step into our life and who give us information and, and provide therapies or do these, these, um other things, actually this lockdowns, been epic cause, like, we had a great Ormond street appointment, um, a couple of weeks ago for Sam and normally that's a whole day off work, like that's, potentially three hours driving in, um, you know, however long appointment, um, probably need to go to the toilet and have something to eat before we do another three hours drive back. So that's like, six, seven, eight hours in the day. I was wearing my running stuff, Zoom call, you know, the doctor came through, done and dusted in 15 minutes. Like that is a proper benefit. But for those people who really touch your life, you know, like you say your theatre where you get to engage and you get to provide that physical sensory experience, um, yeah. You can't, you can't replace that.

Amber (29:21): And so we've spoken about some positive changes that have happened within lockdown. Are there any changes you hope will support people with profound, multiple learning disabilities in the future influenced by this time in lockdown?

Rachel (29:32): So one of the things that I really hope um, has it changes, is a level of empathy, you know, I think before, well, now since lockdown, pretty much everyone in the whole world knows what it's like to be going through life with a certain set of priorities, a certain number of things in the diary, a certain set of expectations and an ease and a normality about life and the way things go. And then it all change. And suddenly everything be very different. And we having to and the, the, discourse and the confusion and the uncertainty of life being very different. And so I hope whenever I talk and do training and stuff and try and share with some of the people and professionals and stuff, what life is like and about that transition, they can tap into the emotions and the realities that they've experienced through this lockdown process. Um, I really, really hope, um, like I say, through the training and stuff that, um we have the opportunity to stop and to really re-evaluate our values and our mission and our expectations as professionals for families, um, and consider ways in which we can provide a more equitable system, a more reciprocal system where it's not just me as a professional saying what has to be done and when it has to be done, um, you know, before, uh, the, you know, the, the physiotherapist wanted to book a meeting with me to discuss something, then I'd get a letter in the post saying, so this is the date that I can do. And can you do it then and come to this place? And I need to say like, either be like, yeah, fine, I'll put that on my pile of, um, my inbox pile of, sort of, letters or, um, zip it into the diary. Or I'd like, spend the next 24 hours trying to get hold of that person to try and rearrange that appointment because it didn't suit me and whatever else. And now we've got the chance, what's happening is professionals are having to meet families where they're at because the families can't extract themselves and take them to where the professionals are. And I hope that is something, that ideology, even if that physically isn't going to continue. Although I think it could do for a lot of situations where parents and families have been expected to go somewhere when really, there was many need they could of had that telephone conversation. They could have had that Zoom conference there wasn't, you know, I didn't need to have my child screaming in a waiting room for 30 minutes before I had a five minute dietician appointment, I could have just spoken to the dietician on the phone. I didn't need to spend an hour trying to get disabled parking space. Um, so I really hope that some of the changes in the way in which professionals have, um, step into our lives rather than us having to go and accommodate the professional's priorities and the therapy priorities, um, carries on so that there is, um, an opportunity to, like I say, re-imagine translating what we do practically into a much more family focused and child parent focused practice. And I think this is, you know, everybody's had to stop. We've all had to stop and take a deep breath and it's all been chaotic. And there is, there is a potential and a tendency for us to take what we've done in the past and try and contort and squeeze and make it fit into this new normal. I really, really hope that people will be a bit more risky than that. And will be prepared to say, okay, let's, let's wipe the slate clean and say, okay, what is it that we're trying to do in our service and our therapy and our provision, and how can we do that in a way that meets the needs of the families rather than fits our provision? I think we've got this opportunity and I really, really hope that lockdown. Has the, um, is the catalyst to, to, for that to be reimagined and change for people with PMLD in the future?

Lucy (33:53): That sounds wonderful. Absolutely.

Rachel (33:56): Wouldn't it be?!

Lucy (33:56): Yeah. Wouldn't that be great. Yeah. And again, something that's been echoed by other people that we've spoken to, you know, actually there are these positive things which..

Amber (34:05): And you think if there are number of people saying it, then change is possible because if people are recognizing the same benefits and the same challenges that are coming out of this period, then hopefully that will mean that voices will be heard.

Rachel (34:22): Absolutely. I think that's why I care about the whole bridging the gap. You know, bridging the gap is, is the thing that I really want to strive for because there is this, there is this family voice and there is this collaborative voice from parents. Um, and I think actually we too often are arguing against the people in place to try and support us. And actually what I think when you talk about collaborative voices and louder voices, if we, the parents and the professionals and the specialists, were all united in our voice of turning round and saying to the people who have the structures and the policies and the legislation or whatever, this isn't working or this is how we need to change things. If, if we bridge that gap, how much stronger would our voice be if all the professional bodies and all the parents and all the things were turning around to the government and the people in power, whether it's local, whether it's central and saying, hang on a second, the system Isn't working? So we've got this, we've got this, um, we've got this ideology and policy of collaboration and coproduction all this stuff up, up in the clouds kind of thing. But the time it filters down to the reality for families, it's so different. It doesn't feel like collaboration. It doesn't feel like effective communication. Um, and the things that need to be changed are not things that the professionals who we work with can make anything, can do anything about. We collectively need to use our voice to turn round and say, come on. This could be different, and this can be better. Um, and like you say, if there is a united voice for families and a united voice from the people who are in our lives, trying to support us, then we go, just imagine what we can do.

Lucy (36:15): And the power of, of the people. Cool, well, I think we should leave it there. Thank you, Rachel, on that, on that nice sort of note.

Amber (36:25): And just before we finish, we've got a lovely recording that you did earlier in the week where you were having a chat with Sam, so we'll just play that here.

Rachel (36:35): How are you Sammy? Say hi-a.

Sam (36:38): (Vocalises) Hello.

Speaker 1 (36:42): Do you want to listen to the Gruffalo?

Sam (36:44): Yeah.

Rachel (36:44): Yeah. Would you like to go swimming later.

Sam (36:44): (Vocalises)

Rachel (36:46): Who do you love more? Do you love, listen, do you love mummy?

Sam (36:53): Silence.

Rachel (36:53): Do you love Lucy?

Sam (36:57): (Vocalises).

Rachel (36:57): Oh nice to hear that. Do you want your story back on.

Sam (37:02): Yeah.

Rachel (37:04): Yeah. Love you lots.

Lucy (37:06): And thank you Sam so much for that clip. Um, it's really hilarious to hear that you're loving Lucy more than your mum right now. Uh, Rachel, how does that make you feel?

Rachel (37:16): I was just going to say that that's outrageous that actually I am much nicer than Lucy and, um, that, uh, just because, you know, I am just as beautiful as the 20 year old girl that he prefers at this minute. Um, and, uh, that's about it really. I just, you know, I just don't want to end on and saying all that. And then Sam being like yeah but your not as good as Lucy, are your mum?

Lucy (37:42): (laughter).

Rachel (37:42): Which is essentially, which is essentially what you've done in this podcast.

Amber (37:46): Brilliant. Well, thank you so much.

Rachel (37:48): Been so lovely to talk to you both.

Lucy (37:49): And you Rachel, thankyou, bye.

Lucy (37:53): So what an interesting episode, and I think what was so fascinating about talking to Rachel following Emma and Hugh's episode last week was the real correlation between what they were saying in their hopes for the future and the hope that actually medical professionals and people in their lives will start to think a little bit more about how they can support them by using these virtual technologies and all the good things that have come out of that. So I found that really, really interesting and exciting.

Amber (38:20): I found really interesting, Rachel talking about the hashtag bridging the gap and the training that she's providing, and we will put a link for all the things that we discussed on the podcast on our website notes.

Amber (38:33): I'll also put a link up for the COVID-19 shielding guidance for Children and Young People from the Royal College of Paediatrics and Child Health, which Rachel also mentioned in today's episode.

Lucy (38:44): So up on next week's episode, we have Dr Nicola Grove from Open Storytellers and what we're really excited to talk to Nicola because during lockdown herself and a few others have been running, Surviving Through Story, which has been running on Facebook and has become a bit of a phenomenon. So we're really excited to learn more about it.

Amber (39:07): If you'd like to get in touch with us about the podcast or about any of our future projects, please email us at info@frozenlighttheatre.com. Our website is www.frozenlighttheatre.com/podcast. If you want to look at the specific podcast page, which has links to all our episodes and show notes, as well as a transcript of the episode. If you'd like to find us on Facebook, you can get us at facebook.com/frozenlighttheatre. We are @frozentheatre on twitter and @frozenlighttheatre on Instagram.

Lucy (39:44): And you can listen to this podcast on Apple Podcast, Google Play, Spotify, anywhere else, you would usually find your podcasts and please rate review and subscribe.

Amber (39:54): Thanks everyone. See you next time.

Amber and Lucy (39:56): Bye!!

Jingle (39:56): (Jazzy Music).